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CLAIRE ALWAN BSc (Hons) MSc

THE EXPERIENCE OF OSTEOARTHRITIS IN OLDER ADULTS

A thesis submitted in partial fulfilment of the requirements of the
Open University for the degree of Doctor of Clinical Psychology

November 2000

SALOMONS
CANTERBURY CHRIST CHURCH UNIVERSITY COLLEGE

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AWARD DATE: 20 September 2000

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ABSTRACT

Aims:

This study aims to explore the experience of osteoarthritis (OA) in older adults, drawing on concepts from the literature on chronic illness including social-cognition models (e.g. Self-Regulatory Model) and cognitive concepts (e.g. self-schema).

Design and Participants:

A qualitative research design and Phenomenological Interpretative Analysis Methodology were used. Sixteen participants were interviewed. Ten were recruited from an orthopaedic surgical waiting list source and six from a GP source: age ranged from 67 to 79 years, and history of osteoarthritis ranged from one to 35 years.

Measures:

A semi-structured interview schedule was designed and piloted, based on the research literature.

Results:

Analysis identified the following themes: Demands of OA (pain, impact on activity, and impact on mood); Perceptions of OA (onset/deterioration, cause, label, seriousness, prognosis); Strategies to manage OA (use of health services, changes in behaviour, psychological strategies, appraisal of strategies); Perception of Self (compared to past/future/others) and Contextual factors (age, co-morbidity, waiting list). Links between themes were reciprocal, and a tentative model of OA is presented.

Implications:

A comprehensive model of the experience of chronic illness could provide a framework to guide interventions for direct clinical interventions (e.g. adjustment to chronic illness, pain management, identification of psychological comorbidity) and indirect interventions (e.g. consultancy with other health professionals).

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1. REVIEW OF LITERATURE

1.1 Introduction

The prevalence of chronic illness is on the increase in our society, especially within the older age group who are the fastest growing cohort in the UK (Iliffe, Patterson and Gould, 1998). Chronic illness can impact on physical, social and psychological functioning, but little is known about older people's experience of chronic illness. In this review, some of the reasons why the area of older adults and chronic illness seems to have been neglected are discussed. Osteoarthritis is one example of a common chronic illness experienced by many older people. The nature, management and evidence of the impact of this condition on functioning is examined.

The physical and psychological functioning of people with chronic illness such as osteoarthritis varies widely. Health Psychology has attempted to develop models to explain individual differences in the experience and impact of chronic illness. The Self-Regulatory Model of illness provides a framework to integrate social and contextual factors with individual cognition and affect (Leventhal, Diefenbach and Leventhal, 1992). The evidence for specific components of this model, such as illness representations and coping are examined in relation to chronic illness and osteoarthritis. Finally, the study aims and rationale for a qualitative methodology are discussed.

1.2 Older Adults and the Experience of Illness: A Neglected Area

The terms 'old age' and 'older adults' seem somewhat arbitrary definitions for a portion of the lifespan. However, evidence suggests that examination of the needs of this portion of the population is warranted. The number of older people in our society is growing, especially in the eighty or over age group who are the fastest growing cohort in British Society (Hart, 1997). The majority of illness in older adults is primarily due to the high prevalence of chronic disease, with the majority of over sixty five year olds suffering from at least one chronic condition (Hart, 1990). These chronic conditions contribute to morbidity and mortality in older adults. The majority of people aged 65 or over suffer from at least one chronic condition and many experience two or more simultaneously. Poor physical health and disability constitute a risk factor for affective disorder in old age, and chronic conditions and mental disorder interact (Murphy, 1983). The World Health Organization's definition of health is 'a state of complete physical, mental and social well-being and not simply the absence of disease and infirmity'. Therefore, chronic health problems in older adults pose a challenge for the achievement of the goal of 'health for all' (World Health Organization, 1986).

In addition, Hart (1997) argues that negative stereotypes about elderly people held by health-care professionals and sometimes by older people themselves, can be barriers to the provision of optimal treatment for older people. Such stereotypes include a belief that old age is a time of inevitable decline, and that older people are non-compliant, unable to change lifestyles and behaviour, and over-use health services. Evidence to support these beliefs is scarce, however. Data related to bed occupancy

and number of prescriptions dispensed does support the view that older people are disproportionate consumers of health services in comparison to the rest of the population. However, the appropriateness and effectiveness of this utilisation is contentious. Many other studies have indicated an under-utilisation of health services, when seen in relation to their actual need, with older people tending to rely on self-management strategies in response to symptoms, rather than using formal services (Stoller, Forster and Portugal, 1993). Non-compliance is not a phenomenon unique to older people but the implications of non-compliance may be serious for older people due to polypharmacy and the balance of drug interactions. Research on medication compliance indicates that levels of compliance are low when an individual has little knowledge about the condition or the purpose of their medication. This highlights the importance of cognitive factors, such as beliefs about medication and illness. It also points towards the role of communication between health professionals and older people. Some research indicates that older people may be optimistic about their health when comparing themselves to their peers, or their own belief about age-associated decline (Jensen, Counte, and Glandon, 1992). This could have psychological consequences, since self-assessed health is the strongest predictor of life satisfaction in older people (Hart, 1997).

Hart (1997) suggests that interactions between biological, psychological, and social factors are most powerful in older people. Professionals should give recognition to the contextual issues and the impact of socio-economic factors and how physical difficulties are construed and evaluated in relation to the perceived availability of coping resources. Many older people experience concurrent life events such as retirement, bereavement and diminished social and financial status, along with illness,

pain and reduced mobility. Hampson and Glasgow (1996) have carried out a number of studies with older people examining the experience of chronic illness and conclude that,

‘the experience of illness is an important but little studied aspect of the self for older persons and provides a valuable opportunity for applying basic theoretical concepts to real-life concerns’. (p. 57)

According to this view, far from being an unrewarding area, illness in older adulthood may be an especially rich area to study.

1.3 Osteoarthritis: A Common Chronic Illness in Older People

Osteoarthritis (OA) is the most prevalent chronic condition in adults aged sixty-five or over, causing functional impairment, morbidity, and increased use of health care services. The condition is characterised by degradation of articular cartilage and formation of new bone, resulting in inflammation, loss of joint stability and mobility, and considerable pain (O’ Brien, Cousins and Horne, 1998). A series of events, partially understood, results in loss of cartilage and degeneration of biomechanical qualities. Cysts and sclerosis, or thickening of the bone, develop underneath the cartilage and new bone known as osteophytes are formed at the margins of the bones. As the disease progresses, other related tissues such as the synovial membrane also become affected. The most commonly affected joint is the knee, followed by the hip, but it also affects fingers, hand, foot and cervical and lumbar spine. A distinction has

been made between primary OA which has no predisposing factors, and secondary OA in which certain factors predispose the individual. Dekker, Tola, Audemkampe and Winckers (1992) suggest that OA is an end-stage condition which has multifactorial origin. Factors linked to osteoarthritis include obesity, regular participation in vigorous sporting activities and joint trauma (West and Rink, 1997).

There is a strong association between age and presence of OA and at 65 at least one joint group is affected in at least 50% of the population (Dekker *et al.*, 1992). However, not all people will experience symptoms, and it has been estimated that only 30% of individuals with marked radiological OA will experience them. Pain is the principal symptom of OA and initially occurs after use of the joint and is relieved by rest. In later stages of OA pain may also be present during rest and sleep. Other symptoms include stiffness following rest and instability of the joint. Disability may depend on the joint involved and has been grouped into movement categories including mobility, bending down, dexterity, bending arm, and reaching up (Badley, Wagstaff and Wood, 1984). OA is also associated with limitations in performance of roles such as reduction in ability to work, performance of household work, shopping, leisure and recreational activities (Yelin, Lubeck, Holman and Epstein, 1987).

1.3.1. Treatment Responses to Osteoarthritis

Once OA has developed, the medical consensus is to maintain activity levels and avoid inactivity, joint stiffness, pain and depression. Treatment is primarily aimed at alleviating symptoms and prevention of deterioration, including drugs and physical

modalities (e.g. local heat). Surgical intervention involving joint replacement is now a well established procedure. Annually, throughout the world, more than 800,000 primary total hip replacement surgical procedures are carried out on arthritic joints. Joint replacement has been associated with improvements in quality of life and pain (Bernard and Zrinzo, 1999; Knutsson & Engberg, 1999). Current waiting list times for joint replacement surgery on the National Health Service in the UK can be up to two years. Therapeutic approaches include exercise and a small number of studies have examined psychological interventions (Dekker *et al.*, 1992). There has been some evidence to support training in pain-coping skills to reduce the impact of OA (Keefe, Caldwell, Williams and Gil, 1990). However, there is mixed evidence on the effectiveness of educational and behavioural programmes to reduce the impact of OA (Kalfas, Kaplan and Ingram, 1992). There are few studies examining the efficacy of adopting healthier lifestyles in later life, although physical exercise in old age increases physical strength, mobility and cardiovascular status (Elward and Larson, 1992). Research targeting older people with OA has been an area of much neglect, with most studies tending to focus on people suffering from rheumatoid arthritis, rather than osteoarthritis (Barlow, Williams and Wright, 1997).

1.3.2. Impact of Osteoarthritis

A distinction has been made between the physical pain of OA, the psychological impact, and the level of physical disability. Weinberger, Tierney, Booher and Hiner (1990) have highlighted the impact of exposure to stressors on all these dimensions. Increased age is associated with greater physical disability, but not with pain or

psychological distress. Pain and disability are associated with amount of cartilage and bone degeneration, joint immobility and muscle weakness (Dekker, Tola, Aufdemkampe and Winckers, 1993). These authors also found that anxiety, certain coping styles and a tendency to focus on symptoms are also linked with pain and disability.

Dekker *et al.* (1992) have reviewed pain and disability in OA in relation to three levels including the articular level (i.e. changes in the joint), the kinesiological level (e.g. muscular changes) and the psychological level. The review highlighted that pain and disability was related to each of these three levels, but that each alone did not give a clear picture and that an interaction between the three was likely. For example, muscle weakness is associated with pain, but avoidance of pain related activities such as exercise contributes to this problem. They suggest that this avoidance is related to cognitive and emotional interpretations of symptoms. The review also highlighted the role of anxiety, coping style and depression on pain and disability in OA. Many studies in the review were not based on a conceptual framework of pain and disability. Although associations were observed between physical and psychological determinants of pain and disability there was little explanation of these associations.

Briggs, Scott and Steele (1999) compared the impact of OA in two elderly samples and found that people with OA had significantly lower scores than control patients in all quality of life domains, particularly for bodily pain and physical functioning. People with OA experiencing other co-morbid illness had poorer general and mental health. Lam and Lauder (2000) examined the impact of a range of chronic illnesses in the elderly including stroke, OA, asthma and depression. The results suggest that

limitation in daily activities for people with OA was comparable to those who had suffered stroke. OA of the knee had the greatest impact on health related quality of life and also increased the risk of 'sub-optimal overall health'. In a review of several large surveys DeVellis (1993) found that levels of depression were similar in people with rheumatic type diseases compared to those with other chronic illnesses. Disease activity and severity have been positively correlated with emotional distress (Zautra, Burleson, Smith, Blalock, Wallston & DeVellis, 1995) but the relationship between disease status and psychological adjustment is complex. Therefore, although depression is related to pain, when pain is controlled for there is variation in psychological adjustment, and people with similar levels of pain vary in their adjustment (Pimm and Weinman, 1998). Understanding why some individuals are able to manage their illness and minimise pain, disability and distress could help identify areas for intervention.

1.4 Understanding the Experience of Chronic Illness: Health Psychology

The physical and psychological functioning of people with chronic illness varies widely, even within individuals suffering from the same condition (Heijmans, 1999). A number of psychological factors have been studied as determinants of outcome in chronic illness, but much of the work in this area has tended to focus mainly on younger adults. The area of Health Psychology has developed a number of social cognition models that aim to explain the relationship between illness and functioning. These models aim to examine how people create their own models of illness in order to make sense of and deal with their problems. Health-related behaviour is viewed by

the Health Belief Model (Becker, 1974) as the result of an individual's assessment of a number of factors including assessment of the perceived costs and benefits of treatment, perceived seriousness of the condition, and the ability to carry out the behaviour. Studies have provided some support for the health belief model, particularly in relation to compliance, but it has also faced a number of criticisms. Johnston (1994) argues that it may be difficult to separate knowledge of the disease from beliefs about the disease. Also, the focus of this model is on intention to act rather than action itself, and this may have limitations when translating to clinical settings. Williams (1997) suggests that, 'It is clear that there is a need to examine in detail the meaning of illness for the individual concerned'. (p.157). It seems, therefore, that an examination of illness representations and beliefs about illness is valuable in furthering our understanding of individual differences in response to illness and illness-related coping, as well as for the development of interventions to facilitate self-management of chronic illness (Heijmans and de Ridder, 1998).

1.5. The Self Regulatory Model of Illness: A Theoretical Framework

One of the more recent social cognition models is the Self-Regulation Theory (Leventhal, Meyer and Nerenz, 1980). This model aims to provide a framework to integrate social and contextual factors with individual cognition and affect (Leventhal *et al.*, 1992). One of the main features of self-regulation theory is that it proposes two parallel processing systems, the cognitive and the emotional. These two processing systems are largely independent, one creating an 'objective' representation of a health threat and its coping and evaluative processes, and the other the 'subjective' or

their illness (Leventhal *et al.*, 1980). Work with a number of illnesses has identified five broad cognitive dimensions of illness representations. These representations include the following:

- the identity of the illness such as the label and symptoms;
- the cause of the illness;
- the consequence of the illness and impact on the person's life;
- the curability or controllability of the illness;
- the time-line or how long the illness will last (e.g. acute, chronic, cyclical).

These representations are thought to be derived from personal experiences of illness, information from professionals, and messages from the wider culture (Schiaffino, Shawaryn and Blum, 1998). There has been a great deal of interest in illness representations, or illness perceptions, and it is fair to say that this particular aspect of Leventhal's overall self-regulatory model has been the most widely examined empirically. Williams (1997) has examined the application of the self-regulatory model to a cognitive understanding of 'dysfunctional illness behaviour'. He argues that the Self Regulatory Model has limitations in its application as a clinical model to guide intervention as it ignores the 'self-schema'. He proposes an interesting model which incorporates beliefs about the illness, but also includes two further elements to produce an illness belief triad. This triad includes:

- Beliefs about the illness (illness representations).
- Beliefs about the self, others and the world (self-schema).

- Interaction between the illness representation and the other non-illness-related beliefs (elements of the illness representations likely to be influenced by other beliefs).

The relationship between the five dimensions of illness representations is also rather unclear, with some studies finding dimensions highly correlated (Hampson, Glasgow and Zeiss, 1994) and there is also a question of whether individuals use all five dimensions in their models of illness. Heijmans and de Ridder (1998) examined the relevance of the five-dimension illness perceptions model with Chronic Fatigue Syndrome (CFS) and Addison's Disease (AD). They found that evaluations of illness were different depending on the disease experienced. For example, in both CFS and AD they found a four-factor solution which was slightly different in content for each disease. They conclude that dimensions of illness representation may merge according to what is relevant to the disease being studied and suggest the need for research from a disease-specific perspective, rather than the generic five-dimensional structure.

(i) Evidence on Illness Representations

A number of recent studies have examined the role of illness representations in chronic illness and illness related behaviour. These representations have been related to adherence to treatment in a variety of conditions (Leventhal, Deifenbach and Leventhal, 1992), emotional response to symptoms in cancer (Easterling and Leventhal, 1989), the decision to seek health care by people in a community sample (Cameron, Leventhal and Leventhal, 1993), older adults' decision to attend HIV

testing (Siegel, Schrimshaw and Dean, 1999), older women's utilisation of cancer screening (Savage and Clarke, 1998) and coping with chronic illness in people with diabetes (Hampson, Glasgow and Toobert, 1990). Moss-Morris, Petrie and Weinman (1996) examined the role of illness perceptions and coping in functioning in chronic fatigue syndrome (CFS). They examined illness perceptions as measured by the Illness Perceptions Questionnaire (IPQ) (Weinman, Petrie, Moss-Morris and Horne, 1996). This measure was based on Leventhal's model of illness representations and was designed to assess illness perceptions in the context of chronic illness and developed in the areas of diabetes, rheumatoid arthritis and chronic pain. Illness perceptions and emotion-focused coping were related to psychological adjustment and functioning. Illness representations in CFS were more strongly associated with adjustment and well-being than coping, with the 'identity of illness' component being the most predictive of well-being i.e. strong identity was related to poorer well-being. The authors did comment that individuals often have complex interactional models of causes of illness, and that to understand these attributions better there is a need to look beyond unidimensional measures. In terms of coping, seeking emotional support and positive re-framing were positively related to psychological adjustment. In a recent longitudinal study of people with psoriasis (Scharloo, Kaptein, Weinman, Bergman, Vermeer and Rooijmans, 2000), strong illness identity measured by the IPQ was associated with more visits to an outpatient clinic, depression and worse physical and social functioning at one year follow-up.

There is a small but developing literature exploring cognitive representations in rheumatic diseases. Hampson *et al.*, (1994) examined the explicit aspects of OA using structured interviews. They identified the widely shared beliefs which they referred to

as 'folk models' of the disease as well as individual differences in beliefs among participants and their relationship to self management. The study highlighted the shared beliefs with the majority of participants reporting their OA as serious, unpredictable, chronic and incurable. Perceiving OA as intense (i.e. serious with high frequency of symptoms) was related to greater use of health services, negativity about treatment, and poorer quality of life such as pain, role limitation and health perception.

1.5.2. Coping and Chronic Illness

Adjustment to a chronic illness can require major behavioural, emotional and social changes for patients and their families. Loss of health can pose stressful adaptational challenges, restricted autonomy, limited access to social support and associated reduction in coping resources (Hart, 1990). The transactional model of stress, based on the work of Lazarus and Folkman (1984), has provided an influential framework for studying stress and developing understanding of individual differences. The appraisal process is the dominant feature of this model. The model postulates that a potential stressor arouses the appraisal process which includes both the assessment of potential for threat (primary appraisal) and the assessment of the person's capability for coping with the threat (secondary appraisal). Stress results when there is an imbalance between the perceived demand and the perceived abilities to meet that demand. Therefore, there is an important distinction between 'objective' and 'subjective' interpretation, and it is the subjective interpretation of events which is important in predicting distress.

Literature on coping describes coping as a mediator of stress, accounting for the variation in responses between individuals in similar situations and within the same individual over time (Pearlin, Mullan, Semple and Skaff, 1990). Coping theory portrays individuals as active responders to stressful situations who attempt to minimise demand, increase capacity, or both, via problem-solving, cognitive efforts and emotion-focused efforts (Hinrichsen and Niederehe, 1994). The three main coping modalities have been described by Braithwaite (1990) as being efforts to:

- change and alleviate the situation;
- alter or reduce the perceived threats/ create a more positive perception;
- manage the symptoms arising from the situation.

Studies of coping have identified a relationship between coping strategies, functioning and outcome, and have been used to explain variability in response to illness. There is some debate in the literature as to what behaviours and cognitions qualify as coping, and whether this definition includes those strategies which may not be consciously selected by individuals (Newman, 1990). Broad definitions reflect the diversity of coping by including the things people do, either acting or thinking, to increase a sense of well-being in their lives or to avoid being harmed by stressful events (Nolan, 1990). Many models and classifications of coping strategies and resources exist in the literature. The Crisis Theory (Moos, 1986) describes coping as being dependent on three aspects:

- illness-related factors (e.g. severity, time-line, stigma, disability);
- background and personal factors (e.g. gender, role, age, beliefs, culture);
- the physical and social environment.

These all feed into the coping process which follows a pattern of cognitive appraisal of the problem, formulation of adaptive tasks, and coping skills.

The most well-known classification of coping has been postulated by Lazarus and Folkman (1984) who divide coping into problem-focused coping (adaptation of environment) and emotion-focused coping (adaptation to environment). These concepts were derived empirically by factor analysis and the Ways of Coping Questionnaire (Folkman and Lazarus, 1980) has this distinction embedded in its design. Studies using this approach have tended to use pre-conceived typologies and to categorise individuals accordingly. This approach has been criticised for having no clear theoretical basis and for being too simplistic: other research indicates that responses to the Ways of Coping scale form several factors, not just two, and that both problem-focused and emotion-focused coping can be broken down into distinct activities (Parkes, 1984, Aldwin and Revenson, 1987). In contrast, a later generic coping measure, the COPE, (Carver, Scheier and Weintraub, 1989) contains 13 scales which the authors describe as being conceptually distinct.

Debate exists in the coping literature over whether coping constitutes a dispositional orientation to life and willingness to use certain coping responses, or whether coping is situation-specific (Hooker, Frazier and Monahan, 1994). Early studies equated personality and coping styles, but more recently there has been a move away from trait type coping towards a transactional model looking at situation-specific coping. This model postulates that the assessment of coping requires an individual approach to determine which are the most effective strategies for which stressors (Nolan, 1990).

1.5.3. Limitations of coping models

There has been a strong tendency in the coping literature, which may be linked to the dominant western culture, to see problem-solving strategies as the most effective. However, when situations are not amenable to change such as in a chronic illness, these strategies may not be so useful. Lazarus (1993) suggests that all strategies are potentially useful, but that they need to be matched to the stressor. In terms of outcome, there is some evidence linking coping strategies with outcome such as psychological distress, but few studies have addressed this in detail. In relation to coping with illness, strategies such as self-blame and avoidance have been related to poorer adjustment, while positive reframing, social support and planning have been inversely related to distress (Carver *et al.*, 1989). The examination of illness representations in relation to coping has also been scarce, although Chronic Fatigue Syndrome (Moss-Morris *et al.*, 1996) and Addison's Disease (Heijmans, 1999) have been studied. Most studies are quantitative, however, and there appears to have been little exploratory work in this field.

Lazarus and Folkman (1984) have indicated that coping behaviour and emotional states mutually influence each other. A study by Saad and colleagues (Saad, Hartman, Ballard, Kurian, Graham and Wilcock, 1995) examined the relationship between coping and negative affect and indicated that coping strategies were mediators of depression in carers living with a person with dementia. In terms of coping efficacy, it is also necessary to identify at what point coping becomes effective. For example, there may be a time lag between the execution of a coping strategy and effect on

outcome. A related longitudinal aspect is whether coping efficacy changes over time in relation to the progression of illness severity. Townsend, Noelker, Deimling and Bass (1989) have identified two competing hypotheses regarding long term changes in coping. The first is the wear-and-tear hypothesis which suggests progressive deterioration as illness progresses. The second is the adaptation hypothesis which suggests adaptation to the demands of the situation.

An additional important point to consider in relation to coping is the availability of resources required to make certain coping strategies available. For example, in a study of elderly informal carers (Hodgson, 1997), participants communicated that they would seek help from friends and family if only there were any available or willing; or that they would maintain interests outside of caring if they had the time/opportunity to do so. Therefore, a clarification needs to be made between strategies which are being disregarded, and those which individuals do not have the internal or external resources to utilise. Hooker *et al.* (1994) argue that situation-specific coping ignores the role of internal personal resources, such as personality. They suggest that personality may help us to understand the predictors of coping, although few studies have examined both personality and coping concurrently. Illness-related factors, background and personal factors, and the physical and social environment, have largely been ignored in coping research. External resources such as support, personal resources such as personality, and personal factors such as culture, beliefs, and health and social cognitions should be acknowledged in coping models. Potentially, identification of risk factors in this way could enable intervention design and resource allocation specific to individual needs.

1.6 Summary

Although the prevalence of chronic illness is on the increase, there is little research on the experience of chronic illness in older adults. Osteoarthritis is the most prevalent chronic illness in older people, impacting on physical and psychological functioning and quality of life. Social cognition models, such as the Self-Regulatory Model, provide a framework for exploring individual differences in the meaning and experience of chronic illness. This model has been applied to a range of illnesses and focuses primarily on beliefs about the illness (five dimensions of illness representations), coping and appraisal of coping. The acknowledgement of contextual factors and addition of beliefs about the self (self-schema) could expand the model further and provide a comprehensive framework to understanding personal meaning, impact and response in chronic illness. Such information could help inform clinical psychology interventions on an individual and consultancy level with clients and health care professionals.

1.7 Rationale for Methodology: Interpretative Phenomenological Analysis

When there is a relative absence of previous research in an area, qualitative methods are often appropriate (Turpin, Barley, Beail, Scaife, Slade, Smith and Walsh, 1997). This study aims to explore the processes determining and maintaining the relationship between interpretation of symptoms, pain, disability, and distress of osteoarthritis in older adults by adopting a phenomenological approach or ‘insider’s perspective’.

Interpretative Phenomenological Analysis (IPA) draws on phenomenology, or an individual's personal perception or account of an event, and symbolic interactionism, which argues that meanings occur through a process of interpretation as a result of social interactions (Smith, 1996). IPA can therefore be viewed as a qualitative methodology which facilitates co-construction between the participant and researcher emerging from the researcher's engagement with the participants' accounts (Osborn and Smith, 1998). The central premise of IPA is to allow the participant to tell their own story, in their own words, and attempt to explore meanings rather than facts. However, IPA also examines the relationship between account, cognition and behaviour or physical state, and therefore it shares links with the social-cognitive paradigms of health psychology, such as the self-regulatory model. IPA therefore differs from other qualitative methodology, such as Discourse Analysis, which focuses on the importance of language and cultural discourse rather than cognitions per se.

IPA has been used to explore the meaning of chronic illness, such as lower back pain (Osborn and Smith, 1998) and haemodialysis (Smith, Flowers and Osborn, 1997). Smith *et al.* (1997) have suggested that IPA can contribute to understanding of illness by exploring individual conditions (such as OA) and also the general concepts and constructs employed (such as beliefs about illness and coping). Therefore, IPA was adopted in this study to facilitate access to the personal meaning of OA for participants, and also to explore the concepts suggested by the literature on chronic illness.

1.8 Research Questions

The following questions guided the development of the interview schedule and information gathered during the interview.

- What are the demands of osteoarthritis?
- What are people's perceptions of osteoarthritis?
- What strategies do people use to manage osteoarthritis?
- How are management strategies appraised?
- What are the links between demands, perceptions, and attempts to manage osteoarthritis?
- What is the role of contextual factors in the experience of living with osteoarthritis?

2. METHOD

2.1 Design

The study employed a qualitative research design and a phenomenological interpretative analysis (IPA) methodology. A semi-structured interview schedule was designed to address the research questions and data were obtained from face to face interviews.

2.2. Participants: sampling and recruitment

Theoretical sampling in the form of variational sampling was employed (Strauss and Corbin, 1990). This aimed to maximise opportunities to elicit data from individuals along the dimensions of age, sex, and severity of illness. In an attempt to include participants with a range of illness severity, participants were recruited from two populations. Half of the sample were on the waiting list for orthopaedic surgery, and had been placed on the waiting list within the six months prior to the start of the study. These participants were selected as representing individuals with severe illness. The other half of the sample consisted of individuals known to a GP practice who were not awaiting surgery, and were selected to represent individuals with less severe illness.

The inclusion criteria for all participants were as follows:

- Aged 65 or over
- Diagnosis of osteoarthritis
- Non-hospitalised

The study excluded people with severe mental illness or dementia, for whom the interview process may have been distressing or who may not have been able to give informed consent (BPS, 1998). Also, severe mental illness could have introduced additional psychological processes not directly related to osteoarthritis.

The lead clinician of the Orthopaedic Department, and GP practices in a given locality were sent a copy of the research protocol and invited to collaborate in the study (Appendix 1, 2). One Orthopaedic Consultant and two General Practitioners agreed for their patients to be contacted about the study. Sixteen participants took part in the study. Ten were recruited from the surgical waiting list of an NHS Orthopaedic Department and six from a GP practice. Names and addresses of individuals meeting the inclusion criteria were supplied by the two GPs and obtained from the orthopaedic surgical waiting list. An introductory letter with tear-off consent slip (Appendix 3) and information sheet (Appendix 4) was sent to each of these individuals. Individuals who were interested in being involved in the study returned the tear off slip with contact details in a stamped addressed envelope provided. The researcher then contacted individuals directly by telephone to discuss the study and answer any questions before arranging a convenient time for the interview.

2.3. The interview schedule

A semi-structured interview schedule was designed by the researcher to address the research questions (Appendix 5). The development of the schedule was based on the research literature related to the experience of chronic illness, and focused on the broad themes of illness representations, coping and self-management. The structure of the interview was flexible, to allow the participant to include additional information and allow for evolution of the researcher's theoretical ideas according to what emerged from the data.

The design of the schedule followed Smith's model (1995) of identifying broad themes, sequencing themes in relation to sensitive areas, sequencing questions within each broad theme, thinking about possible probes and prompts, using open questions beginning with general questions and moving to more specific.

2.3.1. Piloting the interview schedule

The interview schedule was given to two professional colleagues for comments prior to the first interview and minor amendments were made. The first two participants interviewed were asked to give feedback about the interview process. The interview structure seemed to facilitate participants in expressing their views openly, and they did not have any suggestions for changes to the schedule or additions. Therefore no further modifications were made and the first two interviews were included in the analysis.

2.4. Procedure

2.4.1. Ethical issues

Ethical committee approval was sought and approved from the Local Research Ethics Committee (Appendix 6). Permission was also granted for the study to be carried out by the Chief Executive of the NHS Trust, and the Clinical Director (Appendix 7, 8).

The Older Adult Psychology Service and the Primary Care Counselling and Psychology Service in the area both take referrals for people in the 65 or over age range. The Heads of these services were sent a letter and protocol of the study to inform them of the research and to make them aware should referrals of participants arise during the course of the research (Appendix 9). The Ethics Committee also requested that the GPs of participants should be contacted to inform them of their patients' involvement in the study. This was done following the interview via a standard letter outlining the interview structure (Appendix 10).

It was anticipated that during the course of the interviews, participants would request further information or support in relation to their illness. The Arthritis Research Campaign is one organisation that provides information and support to people with arthritis. A written request was made, informing them of the study and asking for copies of their information booklet for people with osteoarthritis which was made available to participants (Appendix 11). The researcher also maintained clinical awareness throughout the interviews regarding the possible need for assessment of risk of harm. The limits of confidentiality were discussed with each participant before

the interview began, and the researcher took clinical responsibility in relation to the need for liaison with a general practitioner if risk of harm was identified.

2.4.2. Recruitment briefing information

The information sheet gave details about the nature and focus of the interview, the voluntary nature of involvement, and participants were informed that they could withdraw at any time without affecting their care. At the beginning of the interview, the nature of the study was explained once more and there was an opportunity to ask questions prior to the participant signing the consent form and the interview proper commencing.

2.4.3. Debriefing

This section explored how participants were feeling at the end of the interview and whether it had raised any difficult issues for them. They were asked if they would like to add anything further or had any further questions. Participants were again informed about the purpose of the research and asked if they would be interested in providing feedback on the emerging analysis. Participants were offered the Osteoarthritis information booklet from the Arthritis Research Campaign. Participants were also asked if they would like to receive a summary report of the research.

2.4.4. Researcher's Impressions

Following each interview, the overall impressions, thoughts and feelings experienced by the researcher were recorded in the research diary (see Section 2.6.3.).

2.5. Data handling

Interpretative phenomenological analysis provides a framework of strategies for analysing interview transcripts. Smith, Osborn and Jarman (1999) provide a step by step account of analysis. As this study involved a large number of participants and transcript data, the model adopted was the one suggested for analysis of a larger sample, concentrating on exploring and theorising on shared experiences. The analytic stages are described below.

2.5.1. Initial Coding

The primary concern of the analysis was personal perceptions and understanding. However, there was a need at an early stage to identify themes mutually relevant to all participants. These then formed the basis of more detailed analysis. The first step involved reading each individual transcript a number of times, with initial thoughts and points of interest being noted. Each interview was then examined more closely and emerging themes noted. This initial coding was kept at a broad level. Once each transcript had been coded in this way, the codes were examined for ways in which themes could be grouped together. This was repeated for all sixteen transcripts until clusters of themes were generated for each participant.

2.5.2. Identifying Shared Themes

The next stage of analysis was a search for themes reflecting shared experiences for all participants, derived from the researcher's personal interaction with the interview data. All clusters of themes for each participant were examined together to look for general broad categories relevant to all participants, aggregating themes across accounts. Three broad themes were identified.

2.5.3. Analysing Shared Themes

Once general themes had been identified, the next stage involved more intensive analysis. This involved returning to the original transcripts and examining them once again to identify all extracts relating to each of the three broad shared themes. A word-processed file of each transcript was searched and abstracts relating to each theme were copied and pasted into a new composite file. Each transcript was examined in this way. This provided a new body of data for intensive examination.

The next stage of analysis was to examine the shared aspects of participants' experience in relation to each general theme. Extracts within each of the three themes were examined for the emergence of conceptual categories and given a provisional code until a list of provisional codes had been produced for all the extracts within each theme. This list was then examined to see if codes could be grouped together in a meaningful way. The next stage was to group extracts according to these new codes.

2.5.4. Searching for links between themes

The final stage was to explore patterns and links between themes to help understand further the participants' experiences. Diagrams can capture relationships between themes. This initially requires an exploration of inter-relationships between the themes which have emerged from the analysis by examining each category in turn and how it is related to other categories, with a focus on the transcript to verify identified links.

2.6. Validity and Reliability

Standards of quality and rigour are increasingly being applied to qualitative research and are no less essential than with quantitative research (Stiles, 1993). However, it is important that appropriate criteria for judging qualitative research are selected. The aim of validity and reliability checks is to ensure that the analysis and account presented is a sound one which is warranted from the data (Osborn and Smith, 1998). This study employed respondent validity, inter-rater reliability and auditability to maximise the quality of the research.

2.6.1. Respondent Validity

Respondent validity attempts to assess the extent to which the analysis reflects participants' experience and also examines the quality of the researcher's interpretations. The themes, sub-themes and emerging analysis were fed back to five

participants (three from waiting list source and two from GP source) who were asked to judge the accuracy of the analysis and its applicability to their experience, and to make comments about the emerging framework.

2.6.2. Inter-rater reliability

Inter-rater reliability was carried out to assess consistency and repeatability of the analysis. Sections of transcript were selected from four interviews (two from the waiting list source and two from the GP source) for the purpose of assessing inter-rater reliability. An independent rater assigned codes to sections of text without sight of the researcher's own assignments, but using given definitions of codes. Inter-rater reliability was examined by comparing the codes assigned by the researcher and the independent rater and is reported in Section 3.6.

2.6.3. Auditability

The interaction between the researcher and the research produces the data (Charmaz, 1995) and therefore the researcher needs to be aware of potential biases or assumptions throughout the research. This interaction was monitored via a research diary kept by the researcher throughout the study which is available for inspection in Appendix 12.

3. RESULTS

3.1. Participant Details

Basic characteristics of the sixteen participants (ten from surgical waiting list source and six from GP source) are summarised in Tables 1 and 2. Pseudonyms are used throughout to maintain confidentiality and any identifiable information has been changed. There were thirteen female and three male participants, ranging in age from 67 to 79 years. History of osteoarthritis ranged from one to 35 years, and eight participants were experiencing concurrent health problems.

Table 1. Participant details: participants recruited from Orthopaedic surgical waiting list for joint replacement

Participant Name	Gender	Age	Site of OA	History of OA	Time on waiting list	Living arrangements
Jane	Female	68	Both knees	15 yrs	3 months	With husband & daughter
Sarah	Female	73	Knee	11 yrs	2 months	With husband
John	Male	68	Hip	2 yrs	4 months	With wife
Jenny	Female	75	Knee, hip, spine	20 yrs	4 months	Alone (warden)
Lillian	Female	78	Both knees	2 yrs	3 months	Alone (warden)
Steven	Male	79	Hip	2.5 yrs	6 months	With wife
Julie	Female	73	Both hips, spine	2 yrs	6 months	With husband
Henry	Male	67	Hip	1 yr	5 months	Alone
Mary	Female	70	Hip	35 yrs	6 months	With husband
Katherine	Female	77	Both hips	1.5 yrs	6 months	With husband

Table 2. Participant details: participants recruited from GP Practice

Participant Name	Gender	Age	Site of OA	History of OA	Living arrangements
Susan	Female	73	Spine, both knees	22 yrs	With husband
Carol	Female	72	Knee	3 yrs	Alone (warden)
Rebecca	Female	78	Spine, hip	9 yrs	Alone
Mia	Female	70	Spine, both knees	35 yrs	With daughter
Dawn	Female	71	Both feet, both knees	10 yrs	Alone
Natalie	Female	79	Knee, hip	30 yrs	With husband

3.2. Results of the analysis: themes and conceptual categories

Using the method of analysis described earlier, individual transcripts were read and re-read, and over 200 initial codes were identified. These codes were organised into clusters for each participant, and commonalities examined across the transcripts. Three broad general themes were identified from this initial stage of analysis. Within each of these three themes, clusters of codes facilitated the identification of conceptual categories. Full results of the analysis and coding in relation to all themes and categories are displayed in Appendix 13. A detailed example of coding of an interview extract can be seen in Appendix 14.

In the following text, themes and their categories are described. The number of respondents who made expressions related to each of the themes is presented. Exemplary quotations have been used to illustrate the themes, and quotations can be

identified by the use of quotation marks. Links between themes are then examined and discussed and concepts linking themes are presented. Links between themes are also presented in diagram form. The results from the respondent validity study and inter-rater reliability study are also presented.

Three initial general themes were identified from the analysis. These were labelled as the demands of OA; perceptions of OA; and attempts to manage OA. Conceptual categories were identified within each general theme. The three general themes and related sub-themes are summarised and displayed in Table 3. Each is then presented in turn.

Table 3: Themes and conceptual categories

Theme	Conceptual categories	No. participants citing theme (n=16)
Demands of OA	• Experience of pain	16
	• Impact on activity	16
	• Impact on mood	13
Perceptions of OA	• Onset and deterioration	12
	• Cause	16
	• Label: condition and mechanism	15
	• Seriousness	16
	• Prognosis	16
Attempts to manage OA	• Medical/health strategies	16
	• Behavioural strategies	16
	• Psychological strategies	12
	• Appraisal of strategies	14

3.2.1. The demands of osteoarthritis

When discussing the impact of osteoarthritis and the demands it places on people's lives, participants discussed a range of issues. The main categories included pain, impact on activity (including mobility, activities of daily living and social activity), and impact on mood.

(i) Pain

All 16 participants talked about pain as a symptom of their osteoarthritis. Three main categories emerged when participants talked about pain: the intensity of pain, the pattern of pain and factors related to pain. These are summarised in Table 4.

Table 4: Categories generated for the experience of pain

Theme	Conceptual categories	No. participants citing theme
Demands of OA: Experience of Pain	Intensity	
	(i) persistent 'ache'	10
	(ii) sharp 'stabbing'	8
	Pattern	
	(i) continuous	9
	(ii) cyclical	7
	Exacerbating factors	
	(i) walking	10
	(ii) standing	5
	(iii) bending	2
	(iv) twisting	3
	(v) lying down	2

Participants used a variety of terms to describe their experience of the intensity of pain. Ten participants used the word 'ache' to describe their experience of persistent pain.

'It's like, you could say, like a toothache, you know, it's gnawing.'
(Katherine)

'More of an ache, it's there all of the time, yes. It doesn't come and go. I suppose you would say it's a sharp pain, it's like having tooth ache all the time.' (Lillian)

Many also described a second kind of pain, such as 'sharp' or 'stabbing' to describe specific incidences of pain experiences, often in addition to the experience of 'aching'.

'Well, when I get the pain here it feels like somebody digging, digging a, digging a knife or something in you, you know.' (Jane)

'This in my leg here, there is a dull ache, but I get like a really sharp stabbing here, well I describe it as a red hot poker there.' (Julie)

When describing the pattern of pain, nine participants described pain as continuous and described the experience of persistent pain.

'Oh, it's with me every day dear. Every day, just like a toothache it never goes away.' (Jenny)

‘It’s always there, it aches and burns all the time, even sitting here I’m aware of it. It’s never completely gone. It’s still there.’ (Mary)

Others described a cyclical pattern of pain with periods of relief, followed by periods of pain.

‘ But if I manage to get comfortable, nothing brings it on until I’m ready to get up, and then it’s a problem.’ (Sarah)

‘ But, um, I must admit I don’t feel I have the continuous pain that some people seem to get with it. I’m lucky that I can sit with it, and normally in bed it’s not too bad, depending how you sort of wake up sometimes.’ (John)

Participants described pain in relation to a number of factors which they identified as exacerbating pain. This included walking, standing, twisting, lying down and bending.

‘Yeah, I could force myself to walk. But it was so painful.’ (Henry)

‘ And if you’re walking along, you know in the town, and people, er, walk in front of you that you’ve got to pull up sharp, that really, you could cry out then.’ (Jane)

‘Bending, very bad. I bend in the middle of the floor and unless I’ve got something to, it’s not only difficulty with bending it’s pain with bending, it’s painful.’ (Rebecca)

(ii) Restricted Activity: Mobility/Activities of Daily Living/Social

Comments about the impact of osteoarthritis included a range of factors related to reduced activity, including difficulties with mobility, activities of daily living, and social activity. These are summarised in Table 5.

Table 5: Categories generated for impact of OA on activity

Theme	Conceptual categories	No. participants citing theme
Demands of OA: Impact on Activity	Mobility	
	(i) standing	5
	(ii) walking	16
	Activities of daily living	
	(i) self-care (e.g. bathing)	12
	(ii) shopping	5
	(iii) housework	10
	Social activity	
	(i) general social contact	5
	(ii) attendance at formal activities (e.g. bowls)	6

Participants discussed the impact on mobility in relation to inability to stand for long periods, and the inability to walk distances. Eight participants described the need for an aid such as a wheelchair or a stick when walking. Activity had been curtailed considerably as a consequence.

‘ Well I would hate to have to walk down the road to post a letter now. I wouldn’t be able to get back. Not unless I sat on the wall, if I had two or three sits on the wall’ (Steven).

‘Not very good I’m afraid. I can’t walk very far. Can’t go up the town or nothing. I’m more or less housebound, you know.’ (Mia)

Difficulties with mobility and flexibility were also discussed in relation to activities of daily living, such as shopping, housework, and self care. Fourteen participants described difficulty with bathing, due to reduced flexibility of joints.

‘I can’t get into the bath, because you’ve got to get over into the bath, and I can’t lift my legs over the bath. And there’s a shower and all there but I can’t get out when I’m in the bath, which is a nuisance that.’ (Lillian)

‘I just cannot get in the bath. That’s what I would love to do, when I feel particularly tired and painful, to sit in a bath and soak, but I just cannot get in there. And if I got in there I couldn’t get out’ (Julie)

Participants also discussed how reduced mobility impacted on the amount of social contact and social activity participants were engaging in. Some expressed a sense of isolation.

‘Well, as I say, I don’t go out a lot. I used to go to a club that runs Thursday afternoons at (place). It was a knitting club, I used to go there but I can’t get there now.’ (Susan)

‘And they have wonderful visits to all sorts of exciting places. And, of course, I’m now saying, ‘no that’s a whole day out, I can’t do it’. So, yes, I have cut down on those longer things’ (Sarah).

‘But then, my social life was, really, bowls, apart from your normal family social life. Um, and it was my last sporting stop, if you like (laughs). And to have that taken away was hurting.’ (John)

(iii) Mood

Thirteen participants described the impact of osteoarthritis on their mood. The main themes that arose when talking about mood were feelings of anger, frustration, irritability, low mood, and anxiety. These are summarised in Table 6.

Table 6: Categories generated for impact of OA on mood

Theme	Conceptual categories	No. participants citing theme
Demands of OA: Impact on Mood	Anger/ frustration	10
	Fear/ anxiety	5
	Low mood/depression	9

Participants described anger and frustration in relation to limitations in ability to engage in activities, and sense of helplessness.

‘Just, I say I get annoyed at the things I can’t do, but I don’t think I’m bitter about it, you know.’ (Jane)

‘Well I feel like throwing things (laughs). Oh, terrible, yeah, God. She says, ‘Mother, calm down’, you know. But, um, you can’t stop it. Oh, and sometimes you feel weepy. And the pain’s really bad.’ (Mia)

‘ You get frustrated because you can’t do what you er, and you don’t feel like you’d like to feel, and I think it’s a bit of everything.’ (Katherine)

Fears and anxiety were related to current concerns and sense of vulnerability, especially in relation to fear of falling or slipping, as well as anxiety about the future and possible deterioration or increased dependence on others.

‘And because I can’t relax, I hold this so tight (trolley), and I should just be able to hold it lightly and that should take me, but I’m taking that. It’s because I’m afraid of falling. My hands are all red where I hold everything so tight.’ (Lillian)

‘ I’m afraid of falling, or slipping off the stool, or something.’ (Jenny)

‘But I feel that if I have to, can’t cope here, I’d have to get in a sheltered place. I’m hoping against hope that if I can keep no worse than I am I can manage, yes.’ (Rebecca)

Some participants described feeling low in mood at times, and four described features of depression. Assessment of risk was carried out with these four participants, and one participant expressed active suicidal ideation, prompting liaison with GP and referral to mental health services.

‘Um, it shows sometimes, you think, well what have I got to get up for today, I might as well lie here.’ (John)

‘ But it’s just this osteoarthritis that’s getting me down. And I just, I just can’t stick it.’ (Jenny)

‘ Because it does, it really gets you down, and you think you cannot go on any longer. And there doesn’t seem to be anything to help you.’ (Lillian)

3.2.2. Perceptions of osteoarthritis

A number of themes emerged when participants’ talked about their understanding and perceptions of osteoarthritis. These themes included perceptions about the onset and deterioration of the condition; the cause of the condition; the label of the condition

and mechanism behind the symptoms; the seriousness of the condition; and prognosis for the future.

(i) Onset and deterioration

Many participants had a clear idea and memory of the onset of their osteoarthritis, and beliefs about the deterioration of the condition. Categories related to perceptions of onset and deterioration are displayed in Table 7.

Table 7: Categories generated for perceptions of onset and deterioration

Theme	Conceptual categories	No. participants citing theme
Perceptions of OA: Onset and deterioration	Onset	
	(i) sudden	7
	(ii) gradual	2
	Speed of deterioration	
	(i) fast	4
	(ii) gradual	2
	Evidence of deterioration	
	(i) Pain and immobility	5
	(ii) Medical evidence	2

Seven described the onset as sudden in nature, with no forewarning or prior symptoms. Many pinpointed a particular day when they first noticed symptoms.

‘See, when I first had, I had no pre-warning at all when I first got it is in my back it was just that my daughter was born, and then next morning I couldn’t move’. (Susan)

‘But, er, I understand that ten or eleven years ago, I was walking down the drive, on my way into the office, and my knees collapsed under me. And that was the first real sign that I’d had’. (Sarah)

‘It just come on me. And the different residents in here, they can’t understand, because I was all right one day, crippled up the next. It came on so sudden’.
(Lillian)

Eleven participants talked about how their condition had deteriorated. Many discussed deterioration in relation to perceived levels of mobility and reduction in activity levels.

‘ But, um, it’s been getting stiffer and stiffer. And the last year it has absolutely astounded me how immobile I’ve become. It’s literally all happened, seriously, in the last year’. (Sarah)

Two participants used medical information as evidence of deterioration.

‘ I went to the doctor’s he had it x-rayed, he said, ‘Yes, it’s going’ and then had it x-rayed again and he said, ‘It’s completely gone’.’ (Steven)

The speed of the deterioration was also commented on:

‘It really is getting bad, the last few weeks have been really bad. I mean it’s been around for years but the last three years I suppose it has got worse, and

now it's getting, and it was week by week, but now it's almost day by day.'

(Mary)

(ii) Cause

The majority of participants seemed to be searching for reasons to explain the cause of their osteoarthritis, although many were uncertain about cause. Five felt that they had no ideas about cause. Causes included a range of factors including previous lifestyle, wear and tear, other health conditions, inheritance, age and injury. The causes mentioned by respondents are displayed in Table 8. Many seemed puzzled about the cause and were searching a variety of possibilities simultaneously.

'Well I've got my own theories, but the Consultant said largely my size . . . which is believable. But I think a lot of it is probably lifestyle. Um, you knock yourself about at sport, obviously . . . I don't think it's injury as such. You know, purely wear and tear'. (John)

Table 8: Categories generated for perceptions of the cause of OA

Theme	Conceptual Categories	No. participants citing theme
Perceptions of OA: Cause of OA	Previous lifestyle (diet, sport, manual labour, kneeling).	11
	Hereditary	2
	Other conditions (nerves, fibrositis)	2
	Age	3
	Multiple causes	7
	Injury	3

(iii) Label

When talking about their symptoms, participants described their understanding of the condition on two levels: firstly, the label for the condition as a whole, and secondly the mechanism of the condition. Categories related to the perceptions of label of OA are summarised in Table 9.

Table 9: Categories generated for perceptions of label of OA

Theme	Conceptual categories	No. participants citing theme
Perceptions of OA: Label	Condition	
	(i) arthritis	9
	(ii) osteoarthritis	6
	Mechanism	
	(i) crumbling/cracking/corroding bones	7
	(ii) degeneration of joint	7

Fifteen participants had ideas for the name of the condition. Nine participants used the terms ‘arthritis’, and only six of these mentioned ‘osteoarthritis’. When describing their understanding of what was meant by the label they used for the condition, participants described a range of ideas about the mechanism of the condition. A number used vivid terms such as ‘crumbling’ to describe what is happening to their bones, and others described ‘corrosion’ and ‘cracking’.

‘And I saw the x-ray of my hips, and it didn’t look a bit like a hip, it just looks like a squashed mess. Because the bones crack and they crack all the time. It’s a wonder how I’ve got any bones left’. (Lillian)

‘Er, I would think if I didn’t know any better, I would think that the pelvis is cracking up because the way it cracks sometimes.’ (Steven)

‘Well my knee cap is going, it’s worn and it’s crumbling, right. My hip is pulling away and it’s crumbling (laughs).’ (Natalie)

Participants also had images of what was happening to their joint or bones while they were walking.

‘but the way it feels, as if I’m walking and then it feels as if it’s completely come out of it’s socket and it just won’t go.’ (Mary)

‘in fact sometimes if I’m, when I’m out walking, I can’t do a lot of walking really, I just feel that my leg, from here is going to snap.’ (Julie)

(iv) Seriousness

Fifteen participants felt that their condition was serious and only one felt that their osteoarthritis was not serious in its consequences. The categories relating to perceptions of the seriousness of OA are summarised in Table 10.

Table 10: Categories generated for perceptions of seriousness of OA

Theme	Conceptual categories	No. participants citing theme
Perceptions of OA: Seriousness	Seriousness	
	(i) serious	15
	(ii) not serious	1
	Appraisal of seriousness	
	(i) comparison to others	3
	(ii) impact on quality of life	9
	(iii) need for surgery	1

The means by which people evaluated the seriousness of their condition involved a number of factors. These included reduced mobility, impact on activities of daily living such as bathing, pain, impact on others, and need for surgery.

‘Well, I think it’s quite bad. I have to er have a wheelchair, I’ve got a wheelchair. And I can’t get down in the bath.’ (Susan)

‘ Well, I suppose they must be serious for me to have a knee replacement mustn’t they? So I suppose it must be serious, mustn’t it?’ (Jane)

‘I think it’s very serious, because not only am I restricting myself, and what I can do. But I’m causing great inconvenience to other people.’ (Sarah)

Some used comparison with others as a means to assess seriousness. This included comparison with others, and also comparison with other ‘self’ in the past. Some

simultaneously compared themselves to others and past 'self' to describe their own subjective experience of the impact of their illness.

'Well I don't consider it very serious. Um, I suppose I better qualify that because I've seen people with hip that have got a deformity as well. Yeah, so I think there's quite a, there's a range of people a lot worse than I am. Um, but personally it's serious to me because I can't live the life that I've been used to.' (John)

(v) Prognosis

Eleven respondents talked about their ideas about the future prognosis of their illness. Categories related to perceptions about the prognosis of OA are summarised in Table 11.

Table 11: Categories generated for perceptions of prognosis of OA

Theme	Conceptual categories	No. participants citing theme
Perceptions of OA: Prognosis	Assessment of poor prognosis	
	(i) deterioration of symptoms	10
	(ii) spread to other joints	2
	Surgery as indicator of good prognosis	7

All eleven participants described a poor prognosis including fear about future deterioration of their symptoms, and progression of the condition to other joints.

‘I can’t see that, um, it can, I mean I’m seventy-three, I can’t see that I will lose it. I’m hoping that, er, I don’t know I presume it doesn’t spread, it’s a funny word to use. I can’t see that I’ll ever lose it.’ (Sarah)

‘ Well I don’t think it will ever go away quite honestly, not all together. I’m just hoping that the left one won’t be as bad as the right one.’ (Carol)

A number of participants mentioned hopes regarding the outcome of surgery, when discussing their future. Many felt that surgery was the only way that symptoms would improve in the future.

‘I mean if I don’t have it done, I’ll probably end up not being able to walk, sort of in a few years time wouldn’t I?’ (Jane)

‘Well, it’s not going to get any better without an operation, that’s for sure. It’s steadily getting worse.’ (Steven)

3.2.3. Attempts to manage osteoarthritis

A wide range of strategies were mentioned as attempts to manage the impact of osteoarthritis. These strategies clustered under a number of themes including use of

health care and medical interventions, changes in behaviour and psychological strategies. They also talked about their appraisal of strategies.

(i) Use of Health Services:

Participants had used a number of strategies related to medical and health services. These are summarised in Table 12.

Table 12: Use of health services as strategies to manage OA

Theme	Strategies adopted	No. participants citing theme
Attempts to manage OA: Use of health services	Medication	16
	Physiotherapy	5
	Hydrotherapy	3
	Osteopathy	2
	Pain Clinic	1
	TENS machine	2

All sixteen participants had used medication at some stage, such as painkillers or anti-inflammatories.

‘Um, I’m getting to be a regular medicine chest really. I’m not a hypochondriac, but it seems like it when I look at this list of stuff!’ (Steven)

‘Well other than that, all I’ve had is the tablets the Dr gives me, coproxamol I take actually. Yes, painkillers.’ (Dawn)

(ii) Behavioural Strategies

Participants described a number of changes in behaviour as attempts to manage their symptoms. These are summarised in Table 13.

Table 13: Changes in behaviour as attempts to manage osteoarthritis

Theme	Conceptual category	No. participants citing theme
Attempts to manage OA: Changes in behaviour	Rest/activity cycle	10
	Task adaptation	8
	Activity/exercise	8
	Setting limits to activity	6
	Practical aids	10
	Maintaining interests	6
	Heat source	5
	Reading	4

Ten participants described trying to find a balance between rest and exercise. Many were breaking tasks down into small stages with resting in between.

‘ You see, I go out there and do the potatoes I’ve to come back, sit down. Then go and put it in the microwave, then sit down again. I have to do it bit by bit, I can’t do it anything otherwise.’ (Jenny)

Many also described adaptation of tasks to involve less movement.

‘ But whereas the old days you probably pick one up, dry it and put it away, you now put it in neat piles ready to move round the kitchen and, er, and put it away. That’s, and I think that, whatever you do, you tend to think along those lines.’ (John)

Many were also adapting a task to make it more manageable by using mobility aids or practical aids.

‘Well, I had to buy one of these little plastic step stools to get in and out of the bath. But our bath, there’s a ledge, I get right to the end and bring myself up each side, sit myself on that ledge at the end you see.’ (Katherine)

Participants also made links between immobility and stiffness, and were attempting to keep mobile.

‘But if I can get up and walk a little bit about, it’s more stiffness is when you sit too long.’ (Mia)

(iii) Psychological strategies:

Participants described a range of strategies which were psychological in nature, and are summarised in Table 14.

Table 14: Psychological strategies as attempts to manage osteoarthritis

Theme	Conceptual category	No. participants citing theme
Attempts to manage OA: Psychological strategies	Acceptance	7
	Creating a positive perception of problem	4
	Social comparison	5
	Drawing on experience of illness/ difficulties/ loss	7

Seven participants described acceptance of their difficulties, which seemed to be related to acceptance of the lack of control they have over their symptoms:

‘It’s just something you know you get from time to time, and you just sort of accept it don’t you, you know. Not much you can do about it is there.’ (Jane)

‘I mean I just accept it. You can’t do much about it so you’ve got to make the best of what you’ve got.’ (Dawn)

A small number (four) attempted to see a bright side to their situation and attempted to create a positive perception.

‘ I suppose, think that tomorrow it won’t be so bad.’ (Sarah)

Five compared themselves to people in a worse situation as a form of social comparison to evaluate or minimise their own difficulties.

‘I suppose at least I can get about, whereas there’s lots of people that can’t get about. People that are crippled up with it, you know. Must be awful. I know how they feel, you know, but because, as I say they’re worse off than I am, so.’ (Jane)

‘Now one lot whose got cancer very badly, there’s nothing they can do, he’s slowly dying. So when you look at that and, er, you know, compare yourself, in a way you haven’t got any problems.’ (Natalie)

Some drew on their experience of dealing with concurrent or past illness, difficulties, or losses in the past.

‘Well, I suppose it’s like a lot of things in life isn’t it. We’ve all got some problems or other, and the older you get probably worse. And I suppose we’ve learnt to cope some way or another, and to find that we’ve just got to get on with these problems. It’s not always easy, it’s not always easy.’ (Julie)

(iv) Appraisal of strategies

Participants described a number of ways of assessing the efficacy of strategies to manage their symptoms. Evidence of efficacy seemed to be related to whether strategies improved symptoms, prevented deterioration, or caused negative side effects. Categories relating to appraisal are summarised in Table 15.

Table 15: Categories generated from appraisal of attempts to manage OA

Theme	Conceptual category	No. participants citing theme
Attempts to manage OA: Appraisal of strategies	Evidence of efficacy	
	(i) symptom improvement	12
	(ii) distraction from symptoms	3
	(iii) preventing deterioration	4
	(iv) duration of improvement	4
	Evidence against efficacy	
	(i) side effects	6
	(ii) concerns about medication	4
	Source of appraisal evidence	
	(i) self	16
	(ii) others: health professionals	5

Assessments of strategies consisted mainly of reduction in pain or increased mobility, and distraction from the symptoms.

‘And by the end, I’d started to have a taxi along to (name) Road from here half the time, and in the end I was able to go about even without the stick.’ (Carol)

‘And the warmth. It’s warmth, you get that little bit of ease. Yes, you know, you can walk a bit better when they’re warm.’ (Mia)

‘Oh, it makes you think, because I can get wrapped up in a book, particularly if it’s a good one, and I can find if it’s really good I’m wanting to pick it up all the time, and that’s my salvation.’ (Carol)

Four participants mentioned one way of appraising strategies with no immediate benefit was to consider what would be the outcome if they did not adopt the strategy.

‘Because, as is always, you forget some day, ouch, and then you remember, you forgot your pill that morning. So I think it’s probably keeping the pain under control.’ (Sarah)

‘So it hasn’t really solved the problem. But I do stick with it, because as somebody said to me, I could be a lot worse if I didn’t use it.’ (Rebecca)

The length of effectiveness was mentioned and most strategies were assessed as having an impact that was short lived only.

‘Just for a week or two, and then it seems as though your body gets used to it. And you go back as you were. It’s only short lived.’ (Susan)

‘It (bath) eases you for a little while but it doesn’t last very long, but I mean for an hour or so after it feels quite good.’ (Mary)

The negative impact of strategies such as medication and exercise were mentioned, and participants had particular concerns about taking medication.

‘My thing is, if I go and swallow those now, and then later what am I going to do and anyway it makes your head fuzzy, I don’t want that.’ (Natalie)

‘ Well, you know, um, it’s easy to get overdoses isn’t it? Paracetamol.’ (John)

‘It’s worse after that, yes. I have tried that, so all this business of exercise. If I really thought it would do good I would do it, but it doesn’t seem to do any good. It’s just wearing it out faster.’ (Steven)

Evidence to appraise strategies was derived from participants’ own experience of trying different strategies, as well as evidence from Consultants, GPs and other health professionals.

‘Not a lot of help, to be honest. In fact, the last lot I had a few years back, the physiotherapist themselves said, ‘There’s no point in you coming, I’m just not doing any good at all’. (Mary)

3.3. Links between themes: building a model

Each of the three themes and related conceptual categories were examined in turn for evidence of links within themes and between themes and categories. Additional themes were then identified, linking and spanning the original themes. This section examines these links in detail and proposes a tentative model to describe the inter-relationship of themes.

3.3.1. Reciprocal links between themes

Examination of the links between the three core themes identified inter-relationships and reciprocal links within and between all three themes via links between the individual conceptual categories. Limited space restricts a detailed examination and presentation of every relationship between each of the many individual conceptual categories. Therefore key examples of links between themes are presented here, and diagrammatical representations used to illustrate intra-theme and inter-theme relationships further.

An illustration of these reciprocal links is presented in Figure 2, which highlights the relationship between categories within the Demands of OA theme.



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bones, were related to immobility in some cases where participants felt that mobility or exercise was contributing to the problem.

There was also a relationship between Demands of OA and Strategies to Manage OA. For example, pain and immobility prevented some people from engaging in exercise. There were also links between Perceptions of OA and Strategies to Manage OA. For example, perceptions of poor prognosis prevented engagement in strategies, and beliefs about the cause and nature of the condition affected the choice of strategies adopted.

3.3.2. Appraisal

Appraisal initially emerged as a sub-theme related to Strategies to manage OA. However, closer analysis identified appraisal as featuring across the three themes in terms of appraisal by themselves and others of symptoms, perceptions about the nature of the condition, and the effectiveness of strategies adopted.

3.3.3. Perception of the self

Detailed examination of the relationship and links between themes facilitated the emergence of a new super-ordinate theme, spanning the three core themes. This theme was labelled as the experience of the self. As participants described the experience and impact of OA such as pain and immobility and their perceptions of the condition,

they often compared themselves to other selves (i.e. other people) and also to other forms of themselves in the past and in the future. The comparison of self to other people has been presented earlier in the results. Therefore, the following section concentrates on comparison of self with other selves in the past and future, and specifically highlights associated issues of loss and threat.

Many participants described the impact of OA in terms of loss in relation to themselves in the past, such as past roles, relationships, activities and pleasure.

‘And I mean gardening, I used to love the garden. And I’m not a person who takes very kindly to sitting down a lot or watching television either.’ (Julie)

‘Well yes, I mean I’ve always been a walker really. Walking, wouldn’t think nothing of walking round the shops, but just now I just can’t do it.’ (Jane)

‘We’ll be honest about it, it has affected our sex lives for one thing. We’ve always had a very good active sex life, and I feel unhappy now because I can’t do it so much, because I feel it’s unfair to my husband.’ (Mary)

Some described loss of independence and increased reliance on other people:

‘Because I always done my own shopping and everything, now I have to get other people to do it for me.’ (Lillian)

Others described themselves in relation to their perception of age related factors:

‘Old, and as a consequence, disappointed. It’s because I hadn’t expected to be so old so early (laughs)’. (Sarah)

‘Oh don’t get old. You get older, and as I say, you don’t, you feel the same in your mind. But it’s your body just, er, gets old doesn’t it?’ (Jane)

‘Erm, well bearing in mind my age, I suppose I don’t do too badly. But I mean, I don’t, I don’t think I am in such good health as I was a few years ago. I shall be 78 in (month), so you don’t expect to feel like you did several years back.’ (Katherine)

Others defined themselves in relation to fears and hopes about themselves in the future.

‘But that’s the only one thing, I kind of feel, I don’t want to be in a wheelchair and all that . . . But I sort of dread that day.’ (Natalie)

‘If it’s true what they say, that once the hip operation’s done there’s no pain . . no reason why I shouldn’t start walking round the block with a couple of sticks or whatever.’ (Steven)

3.4. A model of the experience of osteoarthritis

The results of the analysis of themes and conceptual categories, and the relationship between themes were organised into a framework for understanding the experience of osteoarthritis. A diagrammatical representation of the model is displayed in Figure 3. This model highlights the nature of the three core themes and related conceptual categories, and illustrates reciprocal relationships between the Demands of OA, Perceptions of OA, and Strategies to manage OA. Perception of the self (past, present and future) and Appraisal (by self and others) span all three themes. Contextual factors such as age, concurrent illness and the nature of the waiting list for surgery surround the model.

CONTEXTUAL FACTORS e.g. age, concurrent illness, waiting list for surgery

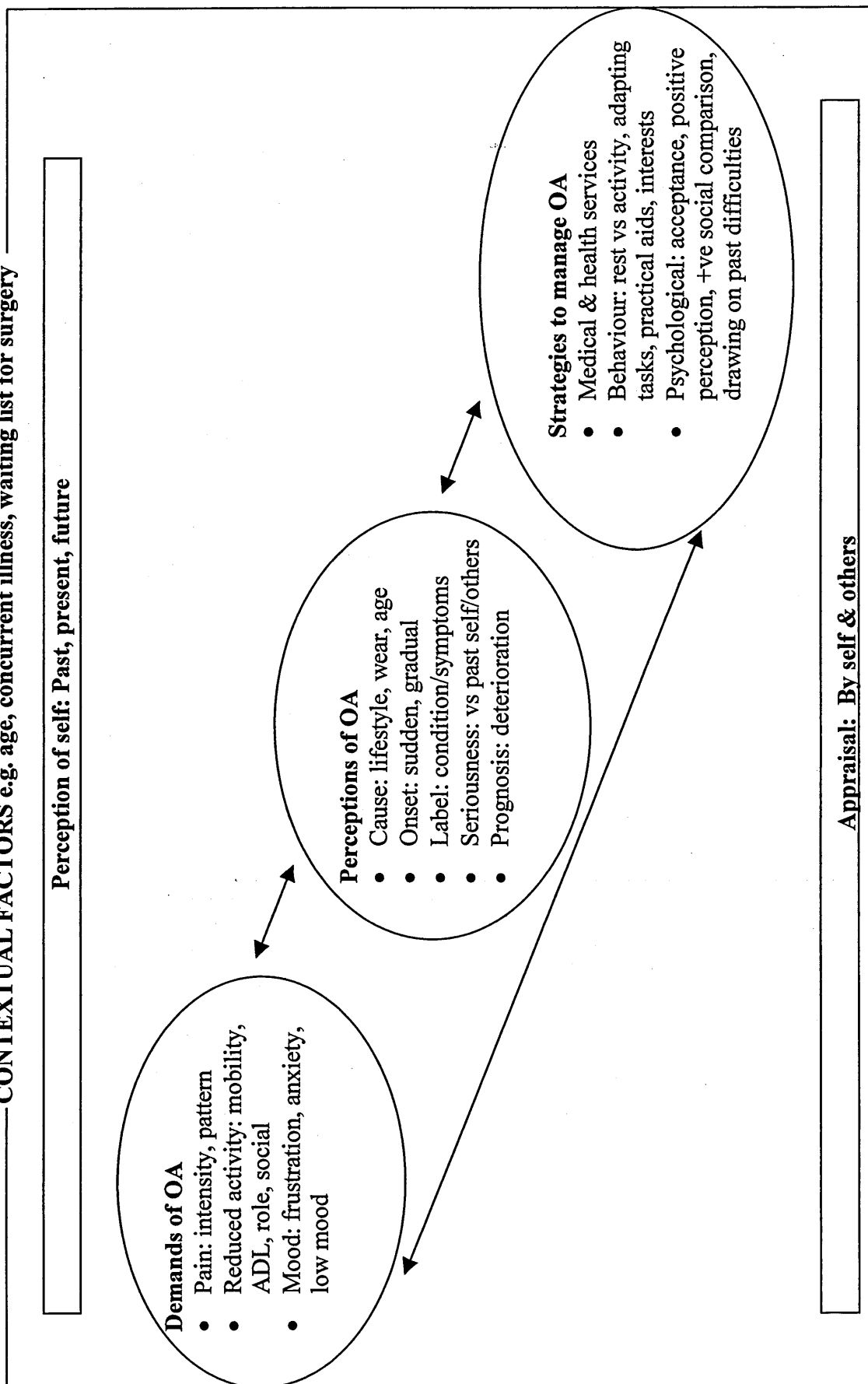


Figure 3: A Model of the Experience of Osteoarthritis: Links between Themes

3.5. Results of the respondent validity study

Five participants (three from the surgical waiting list source and two from the GP source) were re-interviewed and asked to give feedback on the accuracy of the themes and categories generated from the analysis. They were also asked whether the emerging model reflected their experience. Overall, all five participants reported that the analysis reflected their experience. The findings of the respondent validity study are summarised in Appendix 15.

3.6. Results of the inter-rater reliability study

Out of 71 text units, there was agreement on the coding assigned to 66 text units, giving an inter-rater agreement of 93%. The corresponding Cohen's Kappa value was 0.9 (Siegel and Castellan, 1988).

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THE EXPERIENCE OF OSTEOARTHRITIS IN OLDER ADULTS

A thesis submitted in partial fulfilment of the requirements of the
Open University for the degree of Doctor of Clinical Psychology

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4. DISCUSSION

4.1. Overview

The results of the study are discussed in relation to each of the original research questions. Results are compared to the existing research, acknowledging the similarities and differences in the findings. Next, the model developed from the results of this study is discussed in comparison to existing theory. Methodological issues and limitations are considered. Finally, the clinical implications of the study and recommendations for further research are presented.

4.2. Personal model of osteoarthritis

Personal models of illness have been defined as people's representations of their illness, including disease-related beliefs, emotions, knowledge and experience (Skelton and Croyle, 1991). The results of the current study indicate that participants hold multidimensional personal models about their experience of OA. This study suggests that participants could be viewed as 'experts' on the experience of their illness, having rich and complex ideas about the demands the illness places on their lives, their perceptions about the illness, and experience and appraisal of a repertoire of coping strategies. This is consistent with the research of Hampson and Glasgow (1996) who carried out a comparison study of personal models of illness in older people suffering from OA and non-insulin-dependent diabetes. They found that

models of illness became more complex as a result of personal experience of illness, and that personal experience of illness may be linked to expertise.

Participants held perceptions of their condition in relation to each of the five illness representations identified by Leventhal and colleagues in the Self Regulatory Model of illness. For example, they had personal perceptions about the identity or label of the condition, the cause, timeline, cure or prognosis and the consequences of their OA. However, the complexity and detail of each of the five representations did vary, with participants expressing most complex perceptions about the consequences, or impact, of OA. This emerged as a theme in its own right during analysis, and was the area which participants talked about the most. There is some evidence to support the view that the five-dimensional structure of the Self Regulatory Model may vary in structure and complexity according to the condition. Heijmans and de Ridder (1998) compared illness representations in two chronic conditions (Chronic Fatigue Syndrome and Addison's Disease) using the Illness Perception Questionnaire. They examined the factor structures underlying beliefs about the two conditions and found that the dimensions of illness representation merged according to what is relevant to the condition under study. Their results indicated the disease-specific nature of illness beliefs and suggest that structures other than the five-dimensional model of the self-regulatory model may exist.

4.3. The demands of osteoarthritis

Participants presented coherent views about their experience of the demands and impact of OA. The three main areas that arose were the experience of pain, impact of OA on activity including mobility, activities of daily living and social activity, and impact on mood. These three areas are similar to research on the impact of arthritis generally, in terms of the multidimensional experience of arthritis. The Arthritis Impact Measurement Scale (AIMS) (Meenan, Gertman and Mason, 1980) has been developed to assess functioning and well-being in people experiencing arthritic conditions. The three subscales of this questionnaire describe pain, physical disability and psychological disability. Therefore, in the current study, the participants' experience of the impact of OA is consistent with the research in the development of the AIMS, in that participants talked about the impact of OA on all three aspects of functioning.

Looking at each aspect of functioning in more detail, the participants' description of their experience of pain indicated thoughts about the intensity and pattern of pain symptoms, and factors related to pain. Pain has been recognised as a subjective experience, with the need to consider phenomenological and contextual factors (Osborn and Smith, 1998). However, there has been little published work on the personal experience and meaning of pain. The experience of pain seemed to be an individual experience for each participant in this study, although there were some common elements. Participants were able to describe their pain in quite vivid detail, often using metaphors such as 'stabbing', 'burning', or 'toothache' as comparison. Some participants described persistent pain with little relief, and some had

experienced this symptom for several months or longer. This history of persistent pain could be compared to the literature on chronic pain. The emotion and behaviour associated with chronic pain has been linked to the appraisal and the meaning of pain stimuli (Williams, 1997). Osborn and Smith (1998) carried out a qualitative study examining the experience of chronic benign lower back pain. One of the main themes they found included searching for a meaning, and inability to explain the persistence of pain. The participants in the current study also held beliefs about the origin of their pain and factors causing or exacerbating pain.

Each participant reported an impact of OA on their daily activities, including mobility, activities of daily living, and social activity. All sixteen participants experienced reduced mobility and flexibility, with related reduction in social activity, especially attendance at formal groups such as sporting or social clubs, and inability to perform tasks independently such as shopping and housework. Weinberger *et al.* (1990) examined the impact of social support in people with OA. They examined the impact of different forms of social support on functional status and stress. They found that tangible support was associated with enhanced physical functioning (e.g. shopping and transport), and a sense of belonging correlated with psychological functioning. Blixen and Kippes (1999) examined quality of life in fifty older people with OA and found that although few formal social support services were used, participants reported high levels of satisfaction with informal support from friends and family. They found that social support appeared to play an important moderating role in pain, functional limitations, and depression.

The majority of participants also had problems with self-care such as a difficulty or inability to bath independently. The levels of disability reported in this study seem to reflect research examining quality of life and disability in OA which have illustrated significantly lower scores on quality of life related to pain and physical functioning compared to controls (Briggs *et al.*, 1999). Lam and Lauder (2000) also recently examined the impact of OA in comparison to other conditions in the elderly, and found that limitations in daily activities in people with OA was comparable to people who had suffered stroke.

In terms of impact on psychological functioning, thirteen participants felt that their OA had impacted on their mood. Many expressed anger and frustration with the pain and limitations imposed by OA and the impact on their functioning and perceived lack of control over symptoms. Feelings of anger and frustration have been identified as components in adjustment to chronic illness. Barraclough (1994) has summarised stage models of adjustment to illness by identifying various emotional 'stages' involved in the adjustment process. This includes shock, numbness or disbelief, followed by acute distress such as anxiety or anger, followed by depression and despair, and lastly gradual adjustment and acceptance. There is little empirical evidence to support the stage theory, as many individuals do not conform to a set pattern, but the stages seem useful as a framework for understanding adjustment. Although the exact nature of adjustment is debatable, there is consensus that adjustment to adverse life events requires some form of processing of the cognitive and emotional impact and significance of events.

Anxiety and fear seemed to be related to perceived vulnerability in relation to risk of injury and possibility of falling, and fears for the future and uncertainty about prognosis. A small number of individuals had 'catastrophic' beliefs about the nature of their condition, especially in relation to the perceived outcome of activity. Beliefs were expressed about the fear of damaging bones further, and bones were often perceived as fragile. Links have been made between anxiety, pain and disability, with anxiety increasing a tendency to focus on symptoms, exacerbating the experience of pain (Dekker *et al.*, 1993), and avoiding pain-related behaviours (Dekker *et al.*, 1992).

Just over half of the sample reported experiencing low mood and one quarter expressed features of depression. These numbers are comparable to studies examining the impact of chronic illness and pain on psychological morbidity (Zautra *et al.*, 1995). Low mood and depression seemed to result from a complexity of factors including sense of hopelessness about the future and perceived inability to control symptoms, and impact on sense of self in relation to limited activities and role.

4.4. Perceptions of osteoarthritis

Previous research on beliefs about arthritis has emphasised the shared beliefs about arthritis. The study of personal models of illness also yields information about individual differences in beliefs. Hampson *et al.* (1994) examined the personal models of OA and identified some of the shared beliefs about OA in older adults. They found that the majority of participants viewed OA as a permanent condition, and most felt that a cure was unlikely. Most people also viewed their OA as moderately or fairly

serious. The current study elicited similar shared beliefs among participants, with the majority expressing the view that their OA is progressive, and has a poor prognosis without surgery. Many also felt that OA was caused by a range of lifestyle factors. All but one respondent considered their OA to be serious. Examination of appraisal of seriousness identified appraisals on a number of levels. In the main, people assessed seriousness in relation to their symptoms such as pain and the impact on their quality of life. However, in addition to this, some used social comparison with others perceived as worse off than them, concurrently with appraisal of personal impact, to come to a balanced view about the seriousness of their condition.

One interesting perception where participants had differing views was their beliefs about the label of OA. This seemed to be a complex perception operating on two levels, firstly the label for the condition as a whole and secondly the understanding of the mechanism of their condition. Only six respondents knew the correct label for their condition, although many used the general term of 'arthritis'. When looking at the understanding about the mechanism behind their condition, half felt that the joint was wearing away, or degenerating, but others felt that the bones were damaged and used terms such as 'cracking' or 'crumbling'. These views seemed to be constructed from the sensations they experienced, as well as seeing x-rays. In some cases, health professionals had given verbal information about OA, but none of the participants had received or sought any written information about their condition.

4.5. Coping: Strategies to manage osteoarthritis

The participants in the current study reported active attempts to manage their condition using a range of strategies including health care utilisation, but also a range of independent strategies including changes in behaviour and psychological strategies. This suggests that this group were actively trying to problem-solve or find solutions to help manage their difficulties. Many participants with a long history of OA had exhausted a number of strategies during their illness, combining the different modalities of coping.

Many participants were attempting to manage disability by adapting the tasks. Klinger, Spaulding, Palatajko, MacKinnon and Miller (1999) examined chronic pain in older adults with OA of the hip and/or knee and found that occupational adaptation was an important method of coping. They found that participants adopted two approaches to occupational adaptation, either changing the way they performed activities of daily living or stopping vocational activities. The participants in the current study used both of these strategies. Many had also attempted to find the optimum balance between rest and activity, again in response to symptoms such as pain.

In terms of psychological strategies, just under half of the participants reported acceptance of their difficulties. This is a rather complex issue as many described acceptance in relation to sense of lack of control over symptoms, possibly indicating an element of perceived helplessness rather than acceptance as a result of cognitive or emotional processing of their experience. Some drew on experience of past

difficulties or loss to highlight their competencies in coping with difficult life events. This could enhance sense of mastery or self-efficacy with managing their current difficulties. Others used social comparison as a method of creating an alternative perception of their difficulties, by comparing themselves to others worse off than themselves. Osborn and Smith (1998) found in their study of benign chronic back pain that participants compared themselves to others. They reported that in their group of nine women aged twenty-five to fifty-five years, social comparison was not always experienced as helpful. Although women compared themselves to those worse off, this exacerbated their fears about their future. The women also tended to make upwards comparisons with their 'healthy' peers and found this unhelpful as a coping strategy. In the current study, participants tended to compare themselves to peers, but those in a worse condition themselves. Many reported this as a helpful strategy for assessing the seriousness of their condition and also as a cognitive strategy for coping with their OA. It may be that the efficacy of social comparison as a coping strategy could be influenced by cohort affects such as age. For example, in the current study participants often had personal experience of peers and friends within their own age group who were experiencing chronic, severe or terminal illness, and had also witnessed the death of peers. Therefore, comparison to others worse off may have been more tangible or 'real' to them.

4.6. Appraisal

In the current study, appraisal featured throughout the main themes of Demands of OA, Perceptions of OA, and Strategies to manage OA. The Self Regulatory Model

does not, however, include appraisal throughout the experience of symptoms, but concentrates on appraisal of coping strategies. There is evidence that appraisal of bodily sensations is an important factor in the experience of those symptoms even before any response is made (Pennebaker, 1982). Participants' appraisal of perceptions of OA such as seriousness and prognosis was a complex procedure, involving comparison to past and future self, as well as social comparison with others. There is little published work specifically on the appraisal process in illness. However, research within the field of stress and coping has identified the importance of the appraisal process. The transactional model of stress includes objective and subjective appraisal as mediators in the experience of stress (Lazarus and Folkman, 1984). The current study therefore supports the importance of the appraisal process as mediating the experience of illness, and expands on the Self Regulatory Model of illness.

Appraisals of strategies were often based on personal experience of attempting strategies and assessing effectiveness in relation to personal indices of efficacy such as pain and mobility. Therefore appraisal of strategies was closely linked to participants' personal model and perception of their condition. Participants often had a long history of illness and had built a repertoire of strategies by trial and error. A few obtained evidence of effectiveness from professionals. Participants had particular concerns about the use of and reliance on medication. Accounts indicate that the decision to reduce or stop medication or other interventions had been a considered one, taking into account the benefits and costs of interventions. This suggests a complex process, based on discordance between patients' and professionals' models

regarding the benefits of interventions, rather than simple non-adherence or non-compliance with instructions.

4.7. The theoretical framework

4.7.1. The link between illness representations and coping.

There is evidence in the literature for relationships between individual illness representations, but the nature of this relationship has been unclear. The results from the current study suggest that relationships between illness representations are reciprocal. The relationship between pain, distress and disability seems to be multidimensional and neither linear nor causal. Most work in this field has indicated that cognitive representations influence affect, but again this seemed reciprocal in the current study, with one exacerbating or influencing the other, rather than a clear causal model.

The self-regulatory model depicts two largely independent processing systems, one concerned with the cognitive representation of a health threat and its coping procedures, and the other the emotional processing system (Leventhal *et al.*, 1992). The interaction between emotion and illness cognition are potentially numerous. Emotional states could influence illness representations by affecting the progress of a disease, altering attention to and interpretation of representations (catastrophic), and affecting behavioural decisions. Schiaffino *et al.* (1998) examined the impact of illness representations on psychological adjustment to chronic illness and found that

the relationship between illness representations, mood and disease severity was dynamic.

Some studies have identified particular illness perceptions as most strongly related to functioning. For example, Moss-Morris *et al.* (1996) examined the regulatory role of illness perceptions in chronic fatigue syndrome and found that beliefs regarding lack of control and serious consequence of the illness were strongly related to disability and psychological problems. Hampson *et al.* (1994) examined the relationship of older people's personal models of OA and found that beliefs about symptoms and seriousness of the condition were consistently related to levels of self-management, utilisation of health care, and quality of life. They found a correlation between symptoms and seriousness, for example those who reported more pain and more symptoms also viewed their condition as more serious.

In the current study, beliefs about pain as an indicator of damage, or a noxious stimulus to be avoided, seemed related to people's unwillingness to engage in activity or to adopt activity as a coping strategy. Literature on pain management suggests that people often believe that the sensation of pain indicates damage and therefore the need to rest. In the current study, the majority of participants used pain as an indication of seriousness and tended to respond to pain by resting until the pain subsided. This is similar to the work carried out by Hampson *et al.* (1994) who found that pain was viewed as an index of disease severity. Waddell, Newton, Henderson, Somerville and Main (1993) have described how the fear-avoidance of pain is related to rest, which is contraindicated in pain management. Therefore, beliefs about pain have a clear link and relationship to the experience of the impact of OA and attempts

to manage symptoms. Beliefs about pain have been linked to psychological well-being, such as feelings of lack of control and hopelessness, and comparisons have been made between the cognitions of those experiencing chronic pain and those who are clinically depressed (Turk and Rudy, 1992).

4.7.2. Perception of the self

The current study identified perception of the self as an important factor in the experience of illness, in addition to perceptions about the condition, coping and appraisal. This presents an additional component to the Self Regulatory Model, and highlights the importance of the wider context including beliefs about the self and self-schema. This supports the argument presented by Williams (1997) who has identified the exclusion of self-schema as a limitation of the Self Regulatory Model. The model Williams proposes incorporates illness beliefs within a cognitive triad including beliefs about the self, and interaction between illness-beliefs and non-illness-related beliefs.

Horowitz (1986) suggests that any major life event, such as chronic illness, challenges our view of the world and requires an adjustment of our schemas to fit the new information. Moorey (1996) has also identified the importance of examining the role of self-schema in the experience of chronic illness. Participants in the current study assessed their situation by comparing themselves in the past, present and future. This revealed a sense of loss, and both threat and hopes for the future. The impact of OA had imposed changes to participants' lives on many dimensions such as inability to

perform tasks, reduced social contact, increased dependence, and related change in role. The illness therefore denied them the opportunity to 'be' the person they were prior to the illness. Studies on a range of chronic illnesses have identified a need to reconstruct a concept of the self which is positive and worthwhile (Yoshida, 1993).

It is possible that basic assumptions about the self could influence the process of coming to terms with physical illness. For example, the belief that it is weak to show strong feelings may prevent emotional processing, or the belief that the self is defined by physical strength may complicate adjustment to reduced mobility and strength.

Perception of age featured in participants' perception of self. Age, as a contextual factor, featured in a variety of ways and was described as a factor in appraisal of current health status. Some participants felt that their OA made them feel 'old', while others compared themselves favourably to their age and their expectations of age-related health. These disparate views of age are reflected in the literature. Jensen *et al.* (1992) have found that older people tend to be optimistic when comparing themselves to their own beliefs about age, while others have found that older people themselves may hold the belief that age is a time of inevitable decline (Hart, 1997). For some participants, the experience of OA threatened their sense of self in relation to their age and their beliefs about age as a time of decline. For example, some described a mind-body split, with an expression of feeling 'young' mentally, and 'old' physically. Participants' experience of concurrent illness also featured in terms of their appraisal of OA in comparison to other health problems in the present and past, and in the adoption of coping strategies such as ability to engage in behavioural strategies, and to draw on experience of coping with illness.

An additional feature of some participants in the current study was the wait for joint replacement surgery. Some participants had suffered from OA for many years, and therefore OA could be described as a chronic condition. However, the anticipation of the outcome of imminent surgery, which was usually one of hope and improvement, complicates the picture of OA in relation to chronicity and adjustment. Although participants expressed loss in relation to comparison with a past self, they also concurrently expressed fears and hopes for the future in relation to possible deterioration and hopes for positive outcome of joint replacement surgery. This uncertainty therefore complicates the picture of chronic illness as a process of adjustment.

4.8. Summary

The findings of this study are most consistent with the Self-Regulatory Model of illness. This model provides an effective framework for the development of more detailed models of adaptation to illness. It is also flexible to the condition being studied and uses common-sense terminology. The relationship between illness representations and physical and psychological functioning seems reciprocal and dynamic, as does the relationship between cognition and affect. The addition of perception of the self and self-schema provides a more comprehensive model for understanding the role of cognitions in illness. The inclusion of the wider context such as age, concurrent illness and waiting list factors provides a framework within which to understand the experience of illness such as osteoarthritis.

4.9. Methodological Issues

Personal models of illness are shaped by personal experience, such as information and interaction with health professionals. The generalisability of this study may therefore be limited by the recruitment of participants from only one Consultant's waiting list, and two GPs. Results may reflect participants' particular experience with those health care professionals and services, and service provision such as information and interaction may vary within GP practices and Orthopaedic Departments. Similarly, this study focused on patients receiving care within the NHS and did not include those receiving private surgery for whom the waiting time for surgery would be shorter. The issues may be slightly different for those individuals for example in relation to perceptions of prognosis and control of OA. In addition, there may be socio-economic differences that were beyond the scope of this study. For example, socio-economic factors may play a role in the experience of the impact of OA via increased accessibility to mobility aids and home adaptations, or help with activities of daily living.

The participants in this study ranged in age from sixty-five to seventy-nine, and did not include older people aged eighty or over. Seven people aged eighty or over were invited to participate in the study, but declined. Six of these were from the GP source, which tended to include individuals in the older age group. The reason why older people may have chosen not to be involved is unclear. Proportionately more individuals volunteered to participate from the surgical waiting list source (ten participants) than the GP source (six participants) although the same number from each source was invited to participate. Although the qualitative methodology did not

involve group comparison or participant matching, placement on the waiting list was used as a crude indicator of illness severity. Participants recruited from the GP source did not appear to be obviously less severe, but the larger number of participants in the waiting list group may have resulted in the sample being skewed towards the more severe end.

The results of this study suggest that the relationships between perceptions, coping, disability and emotional distress are reciprocal and complex. However, the cross sectional nature of the design means that these conclusions are tentative and that nature of causal relationships remain open to question. Disability and emotional distress could determine illness beliefs and coping responses, or vice versa. Alternatively, the relationship could be reciprocal. The nature and relationship of these factors may change over the course of the illness, and therefore these results present a 'snap shot' account of the experience of illness.

Although the researcher presented herself as independent from the medical profession, the collaboration with GPs and Orthopaedic Department was made explicit. It is therefore possible that participants may have viewed the researcher as allied to the medical profession and this may have affected their responses. For example, although it was made clear that individual information would not be fed back to the Consultant and GP, there is a possibility that participants felt their responses may influence their relationship with the Consultant or GP. This could have resulted in emphasising the severity of OA to illustrate the need for surgery, or minimising feelings of frustration and anger regarding the amount of time spent on the waiting list. Emotional components such as anger related to the context of the

waiting list, could have exacerbated the experience of the emotional impact of OA. Therefore the contextual factors particular to these participants again limits the generalisability of results.

The aim of the validity and reliability checks was to assess whether the analysis and interpretation was warranted from the data. The results of the respondent validity study indicated that participants felt the account was applicable to their experience, suggesting that the results represented their views. The results of the inter-rater reliability study were also acceptable, indicating transparency and rigour of the coding process and analysis.

4.10. Clinical Implications

Osteoarthritis is a prevalent condition in older people and has a multidimensional impact on functioning and quality of life. Given the prevalence of osteoarthritis and limitations of medical therapies, there is a clear need to explore alternative approaches to management. The results of this study have implications for clinical psychology on a number of levels, including individual work and work with other health professionals.

Firstly, it is useful to consider the broad clinical implications for working with people experiencing chronic conditions. Clinical work of this nature most often arises within models of working such as liaison psychology or primary care. However, there is a strong case for the role of clinical psychology with people who are adjusting to

chronic illness in the absence of a formal mental health diagnosis, across care groups. This work requires liaison with medical colleagues, and may consist of focused pieces of clinical work with individuals who are experiencing difficulty adjusting to chronic illness. There is some evidence for the efficacy of the application of solution-focused approaches or cognitive behavioural principles to this field. For example, Moorey (1996) has written an interesting chapter entitled, 'When Bad Things Happen to Rational People', which describes the application of cognitive-behavioural principles to working with people with chronic or terminal physical health problems. The Self-Regulatory Model could inform this work by providing a comprehensive but common-sense approach to the assessment of the personal meaning of illness. Using this framework, an individual's beliefs about their condition can be elicited and explored. This approach is not limited to osteoarthritis, but could also be applied as a framework to a range of physical health problems and also to beliefs about mental health problems.

The results of this study indicated that a number of respondents were experiencing severe pain at times, and for some individuals pain was a chronic and continuous experience which did not respond to medical intervention. A very small number of participants had attended a specialist pain clinic, where they had usually received an epidural. Psychological approaches to pain management could complement existing approaches to pain management, and prove helpful in providing new coping strategies to manage pain and related symptoms. Cognitive behavioural approaches to pain management have been well-established and there is some evidence to support the efficacy of such approaches for people with OA. For example, Keefe *et al.* (1990) carried out a random study comparing pain coping skills, arthritis education, or

standard care in older adults with osteoarthritis of the knee. The pain coping skills training involved recognition and reduction of irrational cognitions, attention diversion and changes in activity. Patients in this group had significantly lower pain and psychological distress post-treatment than patients receiving education or standard care.

The results of the current study also highlighted the psychological impact of physical illness. Only a small proportion of participants seemed to be experiencing clinical levels of depression, but none of these were engaged with any mental health support, other than antidepressant medication. Although chronic physical conditions can result in psychological morbidity, clinical levels of anxiety or depression should not be accepted as 'normal' or 'understandable' responses to a situation which does not warrant intervention. Moorey (1996) suggests that cognitive techniques could be useful when excessive distorted thinking may result in unnecessary distress (such as inappropriate guilt) or maladaptive beliefs may prevent the adjustment process from proceeding.

The results also have clinical implications for consultancy with health professionals. There are implications for working with medical colleagues, providing training on the importance and role of information and support, assessing the patient's perception of their condition, and identifying mental health problems requiring referral to specialist services. Dissemination of the application and role of psychological models to the understanding of health could also be an important function of consultancy in this area.

Participants seemed to be receiving little or no information or support while on the waiting list for joint replacement surgery. Participants had little or no information regarding self-management strategies such as levels of exercise and rest. They tended to use strategies by trial and error, basing their judgements on their beliefs, such as pain as an indicator of damage. In this study, participants often viewed pain as an index of severity. However, pain does not correlate with the extent of OA measured radiographically (Dekker *et al.*, 1992). Therefore patients and health care professionals may have different understandings of the assessment of 'seriousness' of the condition. The assessment of personal models therefore has implications for patient-provider interactions, and provides an opportunity for the doctor to 'check out' the patient's understanding of their condition. Knowledge of individual patient beliefs could thus provide information about the concordance between patient and professional views, which could ultimately lead to improvements in patient self-management and quality of life.

4.11. Implications for future research

There has been little investigation of how and why personal beliefs such as illness representations are formed, developed and maintained. Therefore, future research could develop further our understanding of personal models by the investigation of the development and stability of personal models of illness. Two main methodologies exist in the literature for assessing personal models of illness. These include structured assessment via standardised measures such as the Illness Perceptions Questionnaire (Weinman *et al.*, 1996) or via structured interviews (Hampson and

Glasgow, 1996). Future research could assess the effectiveness and clinical utility of different methods of assessing illness perceptions.

There has been little research examining the development and effectiveness of clinical interventions based on the assessment of illness representations. Such work could include interventions targeted at individuals, such as cognitive-behavioural models as described above, and could also include evaluation of interventions aimed at improving communication between patients and health professionals.

Most work in this field has concentrated on the application of social cognition models to the experience of physical illness. However, frameworks such as the Self-Regulatory Model could be applied to personal models of other life experiences. In particular, future research could examine the applicability of the model to the personal experience of mental illness.

4.12. Conclusion

The experience of OA in older adults is a complex and multidimensional experience. OA has impact on quality of life via the symptoms of pain and immobility, which result in reduced activity and impact on psychological functioning. Assessment of personal models of OA, using the Self Regulatory Model as a framework, can identify illness-related beliefs. These beliefs seem to have a reciprocal relationship with coping and functioning. Older people in the current study were actively adopting a number of strategies to manage OA and had built a repertoire of strategies, including

using health services, making behavioural changes, and using psychological strategies. Evidence to appraise these strategies included reduction in symptoms, prevention of deterioration, and absence of negative side-effects.

An expansion of the model to include contextual factors, such as age and co-morbidity, and wider beliefs such as self-schema, provides a comprehensive model of the experience of chronic illness. This model provides a framework to guide clinical interventions with individuals, such as adjustment to chronic illness, pain management, and identification of psychological co-morbidity. It also highlights opportunities for consultancy and liaison with health professionals regarding the role of illness perceptions, psychological components of physical illness, and the importance of patient-provider communication.

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LIST OF APPENDICES

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APPENDIX 1

Consultant Orthopaedic Surgeon

Re: Research Project –

Coping and Self Management in Older Adults with Osteoarthritis.

Dear Mr

I am writing to you regarding my Clinical Psychology Doctorate dissertation which is a qualitative study focusing on the experience of osteoarthritis. My Supervisors are Professor John Weinman at Guys Medical School, and Dr Sue Holtum at Salomons Centre, Christ Church Canterbury.

I am planning to access patients through an Orthopaedic Department and a GP practice in order to capture a range of disease severity, and I wondered if you would be willing for your department to be involved in this research. This would involve access to non-hospitalised patients through the waiting list system. Patients would be invited to participate and would be included in the study on a purely voluntary basis and I would be responsible for coordinating this and conducting all of the interviews. I would of course report back the results of the study to your department, and the department would be acknowledged in any future reports/publications.

I am currently applying for ethical approval through the Local Ethics Committee. I have enclosed a copy of my proposal for your information, but please do not hesitate to contact me if you have any queries about the study. Otherwise, I will contact your secretary in due course to arrange a meeting with you to discuss this further.

Yours sincerely,

**Claire Alwan BSc (Hons) MSc.
Clinical Psychologist in Training**

APPENDIX 2

Practice Manager

Dear

Re: Research Project –

Coping and Self-Management in Older Adults with Osteoarthritis.

I am writing to you regarding my Clinical Psychology Doctorate dissertation which is a qualitative study focusing on the experience of older adults with osteoarthritis. My Supervisors are Professor John Weinman at Guys Medical School, and Dr Sue Holtum at Salomons Centre, Christ Church Canterbury.

The Orthopaedic Department at Hospital are collaborating in this study by providing access to patients. However, I would also like to access some patients through a GP practice and I wondered if you and the partners would be willing for your practice to be involved in this study. I would appreciate it if you would kindly discuss this with the partners.

Patients would be invited to participate and would be included in the study on a purely voluntary basis. I would be responsible for coordinating the study and conducting all of the interviews. I would of course report back the results of the study to your practice, and the practice would be acknowledged in any future reports/publications.

The study has been granted ethical approval from the Local Research Ethics Committee. I have enclosed a copy of my proposal for your information. Please do not hesitate to contact me if you have any questions about the study.

I look forward to hearing from you.

Yours sincerely,

Claire Alwan BSc (Hons) MSc.
Psychologist in Clinical Training
cc. Dr , Dr
 Dr , Dr

APPENDIX 3

Dear

I am working with Mr _____ in the Orthopaedic Department at _____ Hospital and GPs on a study looking at people with joint or bone problems. We are very interested in getting people's views about what it is like to live with these problems. We also want to learn about the different ways people try to manage. We hope that this study will uncover new information that will help us develop services in the future.

Please read the enclosed Information Sheet and take your time to decide whether you would like to be involved.

If you would like to be involved in the study, please complete the tear off slip below and return it in the freepost addressed envelope provided. I will then contact you to discuss the study further. Thank you.

Yours sincerely,

Claire Alwan
Psychologist in Clinical Training

TEAR OFF SLIP

I am interested in being involved in the Joint/Bone Study. I agree for the Researcher Claire Alwan to contact me to discuss the study further.

My name is:

.....

My telephone number (or address) is:

.....

.....

.....

Please complete and return in the freepost addressed envelope provided. Thank you.

INFORMATION SHEET

What is the study about?

This study is looking at people who have joint or bone problems. We are very interested in getting people's views about what it is like to live with these problems. We also want to learn about the different ways people try to manage. We hope that this study will uncover new information that will help us to develop services in the future.

Do I have to take part?

No. Involvement in the study is entirely voluntary. You can also decide to leave the study at any time whatsoever without having to give a reason. This will not affect your medical care.

What will the study involve?

If you do decide to take part in the study, it will involve an interview with the researcher Claire Alwan. The interview will last for about one hour and can take place in your own home or at a convenient location.

The interview will be quite relaxed and will be looking at your experience of living with osteoarthritis. The interview will be recorded on audiotape and the tape will be destroyed once the study is completed. The interview is confidential. Your name will not be used in any reports and all information will be made anonymous.

Will taking part affect the services I receive?

No. Your GP will be informed of your involvement in the study. However, taking part in the study will not affect the health services you currently receive.

How do I get involved in the study?

Please take your time to decide if you would like to volunteer to be involved in this study. If you would like to be involved or want more information, please complete the tear off slip and return it in the prepaid envelope enclosed. The researcher Claire Alwan will then contact you to discuss the study further.

Thank you.

Claire Alwan, Psychologist in Clinical Training.

APPENDIX 5

Semi-structured interview schedule: Outline of themes and questions

This schedule outlines the areas of interest to be discussed during the interview but is not prescriptive and acts only as a guide. The aim is to facilitate the participant telling their own story of their experience of osteoarthritis.

Introduction

Thank you for agreeing to take part in this study. As you may remember from the information sheet I sent you, I am a psychologist in clinical training. I am interested in your experience of what it is like to live with joint or bone problems and I am interested in your own personal view. I hope that the information will help us develop services. Once the study is complete I will send a summary of the findings to everyone who took part.

Discuss limits of confidentiality, participant's choice to stop at anytime, anonymity in reports etc. GP letter. Any questions?
Sign consent form.

Background

(i) Demographic: (Basic demographic information already collected)

- Can you tell me what has been your main occupation? What are the sort of things you usually did? Are you retired? When did you retire?
- Do you live with anyone?

(ii) Health:

- *Open question: How is your health at the moment?*
- *Open question: Please tell me about your joint or bone problems.*
- How long have you had joint or bone problems?
- Where do you have these problems?
- What treatment have you had for your joint or bone problems?

Theme 1: Illness Representations

- *Open question: Can you say a bit about what you understand about your joint/bone problems?*

(i) Identity

- Can you tell me what name you give your joint/bone problems? What is it called?

- What are the mechanisms behind it? What do you think is going wrong?
- What are your symptoms? How often do they occur? How serious are they?

(ii) Cause

- What do you believe caused the osteoarthritis?
- What seems to make it better/worse?

(iii) Timeline

- When you have symptoms, how long do they last?
- Do the symptoms come and go or follow any pattern?
- Has it got better or worse since you first had it? In what way?
- How long do you think you will have osteoarthritis?

(iv) Consequences:

- *Open questions: How does your 'osteoarthritis' affect you?*
- *How does it affect your life?*

Specific areas to explore/prompt (areas taken from Arthritis Impact Measurement Scale):

(a) Physical functioning

- How has it affected your mobility/ physical activities/ household activities/ activities of daily living e.g. washing, dressing, bathing?

(b) Social activity.

- How has your illness affected your social activity or contact with other people?

(c) Psychological Status (anxiety and depression).

- How does your illness affect your mood?

(d) Pain

- Please describe any pain the osteoarthritis causes. How does it affect you?

(v) Cure/control

- Is your osteoarthritis likely to get better or worse? How?
- Do you think that your osteoarthritis is something that can be cured? How?
- Have you found any medical treatment helpful?
- Have you found anything else (non-medical) helpful?
- How much control do you believe you have over your osteoarthritis?

Theme 2: Coping and self management

a) Coping

- *Open question: How do you tend to deal with living with osteoarthritis?*

• How do you deal with the symptoms of osteoarthritis e.g. pain? (self management e.g. medication/ exercise/ diet/ other); (coping strategies e.g. cognitive, emotional, social support) How well does this work?

- How do you deal with the emotional aspect? How well does this work?
- What do you tend to do when you have a bad day?
- Is there anything you do which you find doesn't help?
- Is there anything other people do that helps?

Debriefing

- What was the interview experience like?
- How are you feeling?
- Is there anything else you would like to tell me?
- Is there anything you would like to ask me?

Thank you.

Offer the osteoarthritis leaflet.

I am trying to build up a picture of what it is like to live with bone/joint problems and I would like to check its accuracy once I've seen several people. I need to check back to see if I'm getting it right. I wonder whether you would be prepared to give me some comments on a summary of my findings, at some point, maybe over the phone?

APPENDIX 6

27th October 1999

Mrs Claire Alwan
Salomons Centre

Tel
Fax
Minicom

Dear Mrs Alwan

Illness Representations, Coping and Self-Management in Older Adults with Osteoarthritis

PROTOCOL NUMBER: 61/99 (Please quote in all correspondence)

At the meeting on Wednesday 20th October 1999 the Local Research Ethics Committee reviewed your application form, together with your protocol, patient information sheet and CV.

The Committee would like to reaffirm the fact that on Page 6 of the protocol under Ethics, The NHS Trust is not the REC. The patient information sheet needs a covering/consent letter stating that the study is useful and that you are hoping to uncover new information. The Committee have also suggested that a tear off slip for consent should be included as part of the covering letter and that the letter should have the orthopaedics department and the researchers institute as headed paper except where the patient has come through a GP and the researchers' institute letterhead would be sufficient.

The Committee would also like to see the fact that the tape recordings will be destroyed included in the patient information sheet.

Please send amended paperwork when available, copied 11 times, to Mrs at the above address.

The members of the Committee present agreed that there is no objection on ethical grounds to the proposed study whose title is given at the head of this letter. I am therefore happy to give you our approval on the understanding that you will follow the protocol as agreed.

The project must be started within 12 months from the date of this letter. It is your responsibility as the researcher who made the application to notify the Local Research Ethics Committee immediately you become aware of any information which could cast doubt upon the conduct, safety or an unintended outcome of the study for which approval was given.



INVESTOR IN PEOPLE

If there are amendments which, in your opinion or opinion of your colleagues, could alter radically the nature of the study for which approval was originally given, 11 revised protocols should be submitted to the Committee.

You will no doubt realise that whilst the Committee has given approval for the study on ethical grounds, it is still necessary for you to obtain approval from the relevant Clinical Directors and/or Chief Executive of the Trust in which the work will be done.

Members of the Committee would like to know the outcome of the study and therefore ask that a report or copy of results is sent to the Secretary in due course.

Yours sincerely,

Dr.
Chairman - Local Research Ethics Committee

cc: Chief Executive, Trust.

APPENDIX 7

26th November 1999

Claire Alwan BSc (Hons) MSc
Psychologist In Clinical Training

My ref

Your ref

Please reply to

Dear Claire,

Re: Research Project: Coping & Self Management in Older Adults with Osteoarthritis

Thank you for your letter of 17th November regarding your Clinical Psychology Doctorate dissertation.

I have now had the opportunity to peruse your protocol and confirm that I am happy to grant approval for your qualitative study at to commence.

Yours sincerely,

Chief Executive

APPENDIX 8

Direct Dial and Fax:

E-mail:

Our ref:

Your ref:

29th November 1999

Ms C Alwan

Psychologist in Clinical Training

Salomons

Dear Ms Alwan

Thank you for your letter dated 17 11 99 and I am happy for you to undertake the study of Coping and Self-Management in Older Adults with Osteoarthritis. I look forward to seeing the results.

Yours sincerely

**Clinical Director for Surgery and
Director & Consultant
Accident & Emergency Services**

cc

APPENDIX 9

Older Adult Mental Health Services

Dear

Re: Dissertation – Illness representations, coping and self management in older adults with osteoarthritis.

My final year dissertation for the Clinical Psychology Doctorate is a qualitative study focusing on older adults with osteoarthritis. I am planning to access my participants through the Orthopaedic Department at Hospital and will shortly be applying for ethical approval through the Local Ethics Committee.

Salomons has emphasised the importance of informing relevant Psychology Departments of our research so that you are aware of what is going on in your local area. As my study focuses on older adults I thought it would be best to write to you informing you of the study, and I have enclosed a copy of my proposal for your information.

I am looking forward to meeting with you and later this month. If in the meantime you wish to discuss anything about my research please do not hesitate to contact me via Salomons.

Yours sincerely,

Claire Alwan
Clinical Psychologist in Training

APPENDIX 10

Dr

Research: Coping and Self-Management in Older Adults with Osteoarthritis.

Dear Dr

Re: **DOB**

I am writing to inform you that your patient, _____, has volunteered to participate in my doctoral research dissertation. This study is being carried out in collaboration with Mr _____ in the Orthopaedics Department, _____ Hospital. The study has full Ethics Committee approval.

I met with _____ for an interview on _____. The interview focused on the experience of living with joint/bone problems, including the participants' beliefs about their illness, the impact of their difficulties, and the ways they attempt to manage their difficulties.

Yours sincerely,

**Claire Alwan BSc (Hons) MSc.
Psychologist in Clinical Training**

APPENDIX 11

Arthritis Research Campaign

Dear Sir/Madam,

Re: Research Project –

Coping and Self-Management in Older Adults with Osteoarthritis.

I am writing to you regarding my Clinical Psychology Doctorate dissertation which is a qualitative study focusing on the experience of older adults with osteoarthritis. My Supervisors are Professor John Weinman at Guys Medical School, and Dr Sue Holttum at Salomons Centre, Christ Church Canterbury.

I am accessing participants via an Orthopaedic Department and a GP practice and am interviewing a total of 16 older adults who have osteoarthritis. The study has been granted ethical approval from the Local Research Ethics Committee.

During the interview process it is important that I am able to give participants details of where to get further information or support. I have one copy of your Osteoarthritis Information Booklet, and understand that the limit is 3 copies per application. I am writing to make a special request for 16 copies of this booklet for participants in the study.

Please do not hesitate to contact me to let me know the cost involved, or if you have any questions. I would also be happy to send you further information about the research.

I look forward to hearing from you.

Yours sincerely,

Claire Alwan BSc (Hons) MSc.
Psychologist in Clinical Training

APPENDIX 12

RESEARCH DIARY

May 1999

I am really interested in exploring how people live with chronic illness, particularly in older adults. I first learnt about social cognition models during my Health Psychology Masters and have used the Self Regulatory Model to inform my clinical work (mental and physical health) on a few occasions, but want to look at its applications further. I am clinically interested in work with older adults, but also feel that they have sometimes been neglected in the area of understanding the impact of illness and health improvement. I'm particularly interested in the interaction between representations of illness and coping to explain individual difference. The problem is that the self-regulatory model is quite structured with its various components and the more I read, the more I find endless possibilities for questions I could be asking participants.

During my clinical work with older adults, I met a lot of people who were experiencing aches and pains in relation to arthritis and it seemed very common among that age group. I have also seen relatives with osteoarthritis, and am married to an orthopaedic surgeon so have been exposed quite a lot to thoughts about bone conditions, and interventions such as joint replacement.

July 1999

I've played around with my draft interview schedule so that it reflects the core models I am interested in. I've drawn on some of the general and specific measures in the field like the IPQ and the AIMS rather than making every single question up from scratch. But I also don't want to miss the opportunity to explore further with people their own experience. The IPA approach I'm interested in seems to emphasise the need to facilitate the individual's story-telling. I think that too much structure and questions could inhibit this.

I've come up with a draft interview schedule which I hope will help facilitate story telling, while also exploring some components of the self-regulatory model. I'm sending the draft to my supervisors for comments. I also feel I need to practice the interview so I can hold the schedule in my head and not feel I have to be rigid in the ordering of questions. This reminds me of the seminar Len Rowland gave us about interview design and practising questions— it now feels that his advice really applies to this stage of the research!

August 1999

Positive feedback from supervisors re interview schedule. John Weinman made a valid point about avoiding the word 'osteoarthritis' in my communications with participants, and one of the things we are interested in looking at is participants label for their condition. I quickly had to change all of my participant documents, letters, information sheet etc. before they are sent out – decided to call it Bone/Joint Study instead. I'm looking forward to seeing how the pilot interview goes.

September 1999

I have had a lot of support and cooperation from the medical practice and the Orthopaedic Department and the surgical waiting list sample have been invited to participate first. I am going to send the invites out in batches, just in case everyone volunteers to participate and I have too many and feel I have to interview everybody! I am still waiting to hear from GPs, but all is going well so far. I have been really pleasantly surprised by the support I have had from the medical profession. It's frustrating relying so much on other people to help set up the study but I've had good experiences so far.

October 1999

Presented to the Local Research Ethics Committee – was quite daunting, but they asked some interesting questions. We discussed the merits of informing participants' GPs of their involvement in the study, in case the interview raises issues which they may bring up with their GP. Will include this in the protocol. Very pleased that approval was given, with only minor amendments to be made.

November 1999

Approval from Chief Executive and Clinical Director to access participants from Orthopaedic Waiting list.

January 2000

Carried out my pilot interview this morning with the first participant and raised some issues to consider. Timing seemed fine, just about an hour. I wonder whether it was a bit too structured? Listening to the tape afterwards, I was aware how I tended to move the participant onto the next section of my schedule, without being aware of it. As I become more familiar with my questions I think it will become more fluid. I have decided to include a question on what other people do which is helpful/unhelpful as this lady talked about her husband quite a lot, so broadening to consider the systemic rather than just individual issues.

February 2000

I keep wondering how much reading to do! I have done a lot of reading around the model I am interested in and about Osteoarthritis, but I also want to keep an open mind to a certain extent. Also, bit of a dilemma whether to read methodology, illness models, or older adult stuff. It's helping me think about writing my introduction but it feels a bit overwhelming.

I keep trying to think about the clinical implications – some people have expressed an interest in how this might apply to clinical psychology via older adult work, which is great. But I keep wondering whether the area of Clinical Health Psychology could be acknowledged as a speciality in its own right – bridging the gap between Clinical and Health Psychology.

March 2000

I am glad I have arranged the next lot of interviews as a block over the next few weeks – it is really tiring but I do feel emerged in the study and the subject, especially as the other demands of coursework and placement can feel really distracting.

I initially thought that people on the waiting list would be experiencing more severe OA, but severity just seems so subjective, and not really related to physical indices of severity. One or two participants who seem quite disabled are from the GP sample and are not being considered for surgery, I'm not sure why.

I am feeling drained because today I interviewed two consecutive participants who were both distressed at points during the interview. This prompted assessment of mood and risk, one of them expressed suicidal ideations and I had to liaise with the GP re a referral to the older adult mental health services. It actually went quite well, and I was pleased that it resulted in a referral. It was really strange to be working without the back-up of a clinical team, as I am currently in-between placements. However, I was pleased that I was able to put my clinical skills into practice to manage the situation. I carried out research before clinical training and it felt quite different – now the roles of researcher/clinician are dual and although I am seeing participants in the role of a researcher, the clinical skills proved really important today.

April 2000

Transcribing is interesting is taking so long, about three hours per tape. I've been surprised at how few people know the name of their condition. Some have really vivid images of what is happening in their joints – corroding, crustaceans, snapping etc. No wonder they don't feel like putting much strain on the joint, with fears of making their condition worse. People really seem quite expert in their experience of different strategies to manage OA: health service, behaviour and psychological e.g. distraction techniques. Many have abandoned strategies based on evidence from self and others: e.g. they have felt that they are of little benefit or the benefits are only short lived.

Participants have been talking a lot about the symptoms and impact of OA. This is emerging as a theme in its own right, rather than within the Perceptions of OA theme. The impact seems so complex and multidimensional, impacting on all areas of life including mobility, ADL, social contact, and mood. I have been looking at the links between the themes and it really seems quite complex and reciprocal, including the context and Perception of the Self. I have been playing with some diagrammatical representations of my analysis, which seems to be the best way to try and map the experience of OA.

It is quite difficult with 16 transcripts to keep everything in mind – I have to keep checking back to the original transcripts to see if the emerging model applies to each person. I have been using the method of analysis suggested for larger sample, looking for commonalities, rather than a detailed case analysis for each person. I am pleased I did 16 interviews because people were still coming up with novel themes to a certain extent, but it has meant that the nature of the analysis is slightly different than IPA with a smaller number of participants. I feel that I am engaged with the material, but need to keep checking.

May 2000

I was pleased to hear from participants in the participant validity study that my initial analysis made sense to them and their experience of OA, and that in addition some mentioned that it had helped them think about their condition. Hopefully this means I have not moved too far away from the original meaning during analysis.

APPENDIX 13

THEMES, CATEGORIES and CODES

Theme	Concept	Category	Code
DEMANDS OF OSTEOARTHRITIS	Experience of pain	Intensity	<ul style="list-style-type: none"> • aches • stabbing
		Pattern	<ul style="list-style-type: none"> • continuous • cyclical
		Exacerbating factors	<ul style="list-style-type: none"> • walking • standing • bending • twisting • lying down
	Impact on activity	Mobility	<ul style="list-style-type: none"> • standing • walking
		Activities of daily living	<ul style="list-style-type: none"> • self-care • shopping • housework
		Social activity	<ul style="list-style-type: none"> • general social contact • formal activities
	Impact on mood	Anger	<ul style="list-style-type: none"> • frustration re limitations • frustration re waiting list
		Anxiety	<ul style="list-style-type: none"> • fear re slipping • fear re future
		Low mood/depression	<ul style="list-style-type: none"> • weepy • low • hopeless • suicidal

Theme	Concept	Category	Code
PERCEPTIONS OF OSTEOARTHRITIS	Onset	Speed	<ul style="list-style-type: none"> • sudden • gradual
	Deterioration	Evidence	<ul style="list-style-type: none"> • pain/immobility • medical
	Cause	Factors	<ul style="list-style-type: none"> • lifestyle • hereditary • comorbidity • age • injury
	Label	Condition/ mechanism	<ul style="list-style-type: none"> • arthritis • osteoarthritis • crumbling/cracking • degeneration
	Seriousness	Appraisal	<ul style="list-style-type: none"> • social comparison • impact on QoL • need for surgery
	Prognosis	Indicators	<ul style="list-style-type: none"> • deterioration of symptoms • spread to other joints • surgery +ve prognosis

Theme	Category	Code
STRATEGIES TO MANAGE OSTEOARTHRITIS	Use of health services	<ul style="list-style-type: none"> • medication • physiotherapy • hydrotherapy • osteopathy • pain clinic • TENS machine
	Changes in behaviour	<ul style="list-style-type: none"> • rest/activity cycle • task adaptation • exercise • setting limits • practical aids • maintaining interests • heat • reading
	Psychological strategies	<ul style="list-style-type: none"> • acceptance • +ve perception • social comparison • drawing on past experience of difficulties
APPRAISAL OF STRATEGIES TO MANAGE OSTEOARTHRITIS	Evidence of efficacy	<ul style="list-style-type: none"> • symptom improvement • symptom distraction • preventing deterioration • duration of improvement
	Evidence against efficacy	<ul style="list-style-type: none"> • -ve side effects • concerns about medication
	Source of appraisal evidence	<ul style="list-style-type: none"> • self • others (e.g. health professionals)

APPENDIX 14

EXAMPLE OF CODING: INTERVIEW EXTRACT

<u>Text</u>	<u>Themes/Codes</u>
02: No, I mean I don't . . . I do get pain yes, but I'm not in pain all the time, you know what I mean?	Pain: pattern – <u>cyclical</u>
I: Mm.	
02: Perhaps when I'm sitting down. I mean I couldn't really say I'm in pain all the time.	Pain: exacerbating factors – <u>sitting</u>
I: Right.	Pain: <u>cyclical</u>
02: I mean I do the garden, I cut the grass, and weed and everything, so I do all them sort of things. But, naturally, your mind is the same, but it's your body let, when you're getting older, you know. Er, I just sort of can't, I have to sit down sort of once I've had a little, do a little bit then I can sit down, you know.	Strategies: behaviour – <u>activity</u>
I: Mm. Just rest for a little while.	Self concept: <u>age</u>
02: Yes.	Strategies: behaviour – <u>rest vs activity</u>
I: So what are your symptoms, how would you describe them?	
02: Well, it's hard to explain really. I mean . . .	
I: You said, not much pain, is it stiffness, or not so mobile or...?	
02: Well, sometimes when you keep in bed of a night, if I lay in position, then you perhaps want to turn over. That's when it gets stiff, you know, your knee, it sort of hurts then sort of thing.	Pain: exacerbating factors- <u>lying down</u>
I: Mm.	Demands: mobility- <u>stiffness</u>
02: To turn over and perhaps sort of if you've had your leg out straight, and then you bend it, you know, it's sort of painful then.	Pain: exacerbating factors- <u>bending</u>
I: Yeah. So if you've had your leg in one position for a while?	
02: Oh yes, when I get up in the morning I hobble about a bit, you know. But once I sort of get going I'm alright, and usually I come down and my husband tapes all the soaps for me of a night, like Coronation Street (laughs) so, and Emmerdale, so I sit and watch them, I sit down for sort of an hour, before I get cracking and start doing work like, you know.	Strategies: behaviour- <u>activity</u>
I: Mm. So you just give yourself a bit of time to come round as it were.	Strategies: psychology- <u>distraction</u>
02: Yes, that's it.	Strategies: behaviour- <u>rest vs activity</u>
I: And you mentioned about not being able to walk as far as you'd like?	
02: No, I can't, you know. If I walk, we go shopping like yesterday afternoon, and I can walk around the supermarket and that's enough. I get back here and put my shopping away, I'm glad to sit down then, you know.	Demands: mobility- <u>ADL</u>
I: So what happens after you've been walking for a while? What does it feel like?	Strategies: behaviour- <u>rest</u>
02: Well, it just sort of, well it does ache then, you know. You sort of feel I've got to sit down sort of thing, you know?	Pain: intensity: <u>ache</u>
	Strategies: behaviour: <u>rest</u>

APPENDIX 15

SUMMARY OF RESULTS OF RESPONDENT VALIDITY STUDY

A report of the results of the initial analysis was sent to five participants (three from waiting list source and two from GP source) who were re-interviewed once they had had a chance to read the report. Participants were asked to judge the accuracy of the analysis and its applicability to their experience, and to make comments about the emerging framework.

All five participants agreed with the themes and categories generated from the analysis, providing support for the emerging analysis. They also expressed the view that the results reflected their experience of OA:

‘I think you have covered most of the things that people have told you about osteoarthritis.’

‘I can agree with most of the comments and I think you have covered all the aspects which have been raised thoroughly.’

‘I can say I do identify with your findings from the interviews. Briefly, it is my experience, very true and real for me.’

Participants reiterated points from the analysis to support the emerging themes, but did not suggest any significant changes or additions to the emerging model.